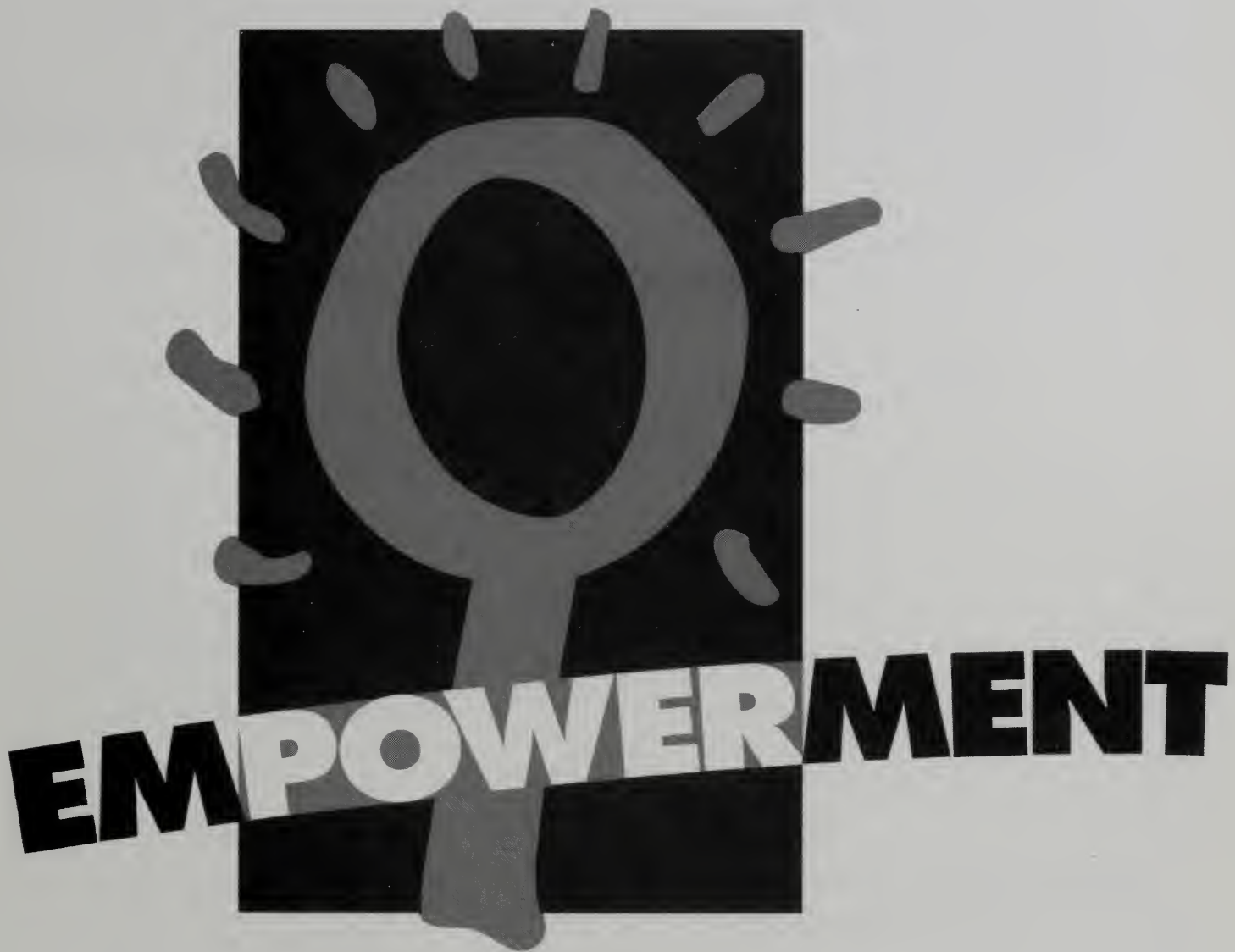


A Strategy for HIV Prevention and
Access to Care Among Women of Color

*Conference Proceedings
and Recommendations*



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I. Summary

A. Purpose

Women of color in the United States are disproportionately impacted by the HIV/AIDS epidemic. While women of color in the U.S. make up about one-quarter of the female population they accounted for over three-quarters of the cumulative AIDS cases and over four-fifths of the new AIDS cases reported among women in 1999. Reports from the 32 areas with confidential HIV reporting indicate that women of color made up three-quarters of the cumulative HIV cases and nearly four-fifths of the new HIV cases reported among women in 1999.¹

To address the devastating impact of the epidemic on women of color the National Minority AIDS Council (NMAC) implemented the *Challenges of HIV/AIDS for Women of Color and Their Families Initiative* in 1994. The initiative is a multifaceted policy and leadership development program for women of color affected by HIV/AIDS. The overarching goals are to enhance leadership by women of color in efforts to:

- develop and implement effective prevention strategies targeted to women of color at risk for contracting HIV infection and,
- improve the quality of life and reduce the AIDS-related mortality of women of color with HIV illness.

In 1995 and 1996 NMAC conducted 11 focus groups with women of color throughout the country to identify their HIV related prevention and care needs and the barriers they experience in accessing these services. In 1997 and 1998 NMAC sponsored two national working conferences for women color. Beginning in 1997 NMAC co-sponsored a series of six policy briefings to educate members of Congress and their staff on the complex issues related to women of color and HIV/AIDS. NMAC brought women of color living with HIV/AIDS, service providers and researchers to Washington, D.C., to serve as panelists for these briefings, thus increasing the participation of women of color in national policy forums. NMAC initiated its regional policy and leadership development skills building training for women of color in 1998.

This report provides a summary of the recommendations and proceedings of the two working conferences NMAC sponsored as part of the *Challenges Initiative*. The first conference, *Empowerment: A Strategy for HIV Prevention and Access to Care Among Women of Color* was held in Houston, Texas, June 23-26, 1997. *Empowerment II: A Strategy for HIV Prevention and Access to Care Among Women of Color* was held in Memphis, Tennessee, August 9-11, 1998. Approximately 75 to 100 African American, Hispanic/Latina, Asian/Pacific Islander, Native American (American Indians/Alaska Natives) and Afro-Caribbean women participated in each

conference, including women living with HIV and service providers. The purpose of these working conferences was to discuss the elements of effective prevention strategies and service delivery models to enhance access to HIV care for diverse populations of women of color. In addition, participants were asked to identify the key components of models for HIV prevention and care, tailored to the needs of specific sub-groups of women of color. These models were designed to integrate holistic approaches to health promotion, disease prevention and empowerment.

B. Format

Each of these conferences brought together approximately 75 to 100 women representing various groups in terms of race/ethnicity, HIV status, age, geographic region and country of origin, economic status and areas of expertise. The participants included African Americans, Latinas, Asians and Pacific Islanders, Native Americans and Afro-Caribbeans, living with HIV, as well as HIV prevention and care service providers. Through the use of exchange fora and facilitated breakout groups, participants developed consensus on a series of recommendations regarding the essential components of effective programs for women of color. These included culturally competent, empowerment-based models for HIV prevention and care services targeted to various groups of women of color. The recommendations also addressed program implementation, funding and resource allocation issues.

This report documents the outcomes of the breakout groups and the recommendations aimed at policy-makers, funders and managers of community-based organizations.

II. Understanding the Problem

A. Women of Color and HIV/AIDS

In the 14-year period between 1985 and 1999 the proportion of women with AIDS in the U.S. more than tripled. In 1985 women represented 7% of the total AIDS cases reported through that year. By 1999, women accounted for 23% of the total AIDS cases reported through that year. The Centers for Disease Control and Prevention (CDC) estimates that there are between 120,000 and 160,000 women living with HIV infection in the U.S., including those with AIDS.²

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Women of color shoulder the greatest burden of HIV/AIDS among U.S. women. While women of color make up slightly less than a quarter of the U.S. female population, they account for the overwhelming majority of the AIDS cases among women in this country. In 1994, women of color accounted for 76% of the cumulative and 78% of the new AIDS cases reported among women in that year. By 1999 women of color made up close to 78% of the cumulative and over 82% of the new AIDS cases reported among women. Among women of color, African American (63%) and Latina (18%) women are the most severely impacted. The 1999 AIDS case rates per 100,000 population by race and ethnicity for women were 49.0 for African Americans, 14.9 for Latinas, 1.4 for Asian and Pacific Islanders, 5.0 for Native Americans and 2.3 for white women. Women of color made up 83% of the deaths due to AIDS among all women 15 years of age and older in 1998. African American women alone accounted for 66% of those deaths and Latinas accounted for 17%.^{3,4}

Up to the mid-1990s injection drug use was the primary mode of exposure among women with AIDS in the U.S., followed by heterosexual contact. In 1994, for example, the proportion of women with AIDS exposed as a result of injection drug use was 41%. Of these cases, 78% were among women of color. The proportion of cases among women with AIDS exposed through heterosexual contact was 38% in 1994, and women of color accounted for 77% of these cases. In the mid-1990s the trends are reversed with heterosexual contact as the leading mode of exposure among women with AIDS.

By 1999 heterosexual contact (40%) represented the leading exposure category among women, and women of color accounted for 82% of these cases. By race/ethnicity heterosexual contact accounted for 38% of the cases among African American, 47% of the cases among Latina, 51% of the cases among Asian/Pacific Islander and 30% of the cases among Native American women in the same year.

In 1999 injection drug use dropped to 27% of the cases of AIDS reported among women, and women of color made up 78% of these cases. By race and ethnicity, injection drug use accounted for 25% of the cases among African Americans, 28% of the cases among Latinas, 11% of the cases among Asian/Pacific Islander and 30% of the cases among Native American women.

However, drug use continues to fuel the epidemic among women, in that a large proportion of women infected heterosexually were infected through sex with an injection drug user. In 1999, for example, 27% of the cases of heterosexually infected women were due to sex with an injection drug user. Among women of color, 24% of the heterosexual cases among African American, 29% of those among Latina, 13% of the cases among Asian/Pacific Islander, and 42% of the cases among Native American women were due to sex with an injecting drug user.⁵ Moreover, more than two-thirds of AIDS cases among women originally reported without identified risk were subsequently reclassified as heterosexual transmission, and slightly over 25% were attributed to injection drug use.⁶

The spread of the HIV/AIDS epidemic among young women of color is particularly disturbing. Of the cases reported from the 32 areas with confidential HIV reporting in 1999, females made up nearly half (49%) of the HIV cases among 13 to 24 year olds. Moreover, young African American and Latina women accounted for more than three-fourths of the cumulative HIV infections reported among females between the ages of 13 and 24 in these areas.⁷

B. HIV Care and Women of Color

Natural history, progression, survival and HIV-related illnesses (except for reproductive tract illnesses) seem to be similar in HIV-infected women and men, according to a recent review of the research on HIV/AIDS. While advances in antiretroviral therapy have led to significant declines in HIV-related morbidity and mortality rates, women are less likely than men to use these therapies.⁸ There are, however, notable gender differences in the receipt of quality HIV care. For example, HIV-positive women in care are less likely than men in care to receive the current standard of care, to know their viral load or CD4 counts, to have had a primary care consult in the last six months and to receive prophylaxis and antiretroviral therapy.⁹ The HIV Cost and Services Utilization Study (HCSUS), a survey of a national sample of HIV-infected adults in the U.S. receiving HIV care, showed that African Americans, Latinos, women, the uninsured and Medicaid-insured experienced inferior patterns of care. Although access to care improved from 1996 to 1998 it remained sub-optimal for these populations. The women in the sample tended to be young, African American, less educated, unemployed, impoverished and under-insured.¹⁰

Women with HIV infection often face greater barriers accessing health care. In addition, they may have the responsibility of caring for children and other family members who may also be HIV-infected. This is supported by the HCSUS study that

found that 14% of women and 6% of men with HIV disease had delayed seeking care for themselves in the previous six months as a result of caring for someone else. Women with HIV disease were nearly twice as likely as men to put off needed care. Moreover, HIV-infected people with a child in the household were nearly twice as likely to put off care as those without children.¹¹ Other factors such as drug use, high-risk sex behaviors, depression and unmet social needs also present barriers for women's use of existing HIV prevention and treatment services.¹²

III. Summary of Key Recommendations

A. Develop and Implement Policies and Mechanisms to Facilitate Meaningful Participation of Women of Color in HIV Policy and Decision-Making Bodies

Federal, state and local agencies should develop and implement policies and mechanisms to facilitate meaningful participation of women of color in HIV/AIDS policy and decision-making bodies. Private funders such as foundations and corporations should target resources to support programs that facilitate empowerment of women of color and increase and sustain their participation in HIV/AIDS-related decision-making bodies.

B. Ensure Delivery of Integrated and Comprehensive Services for Women

Federal, state and local HIV/AIDS funding agencies, private funders and HIV program managers should ensure that services aimed at women of color integrate a comprehensive array of health care and supportive services that specifically address the psycho-social, cultural, linguistic and economic barriers women of color encounter.

C. Ensure Delivery of Culturally Competent HIV Prevention Interventions

Federal, state and local HIV/AIDS funding agencies, private funders and HIV program managers must ensure that all HIV prevention interventions aimed at women of color are culturally competent and delivered in the primary language spoken by the women. These services must also be gender focused, and linguistically and developmentally appropriate. Special attention must be aimed at developing prevention interventions that are appropriate for young women, women of childbearing age and women over 50 years of age. Interventions targeted to African Americans, Asians/Pacific Islanders, Latinas and Native Americans must incorporate the cultural variations found within each sub-population of women. The messages and interventions must provide a context that reflects and relates to the realities faced by women within these specific sub-populations and address the many

Since many women at risk for HIV are substance users, interventions must integrate HIV prevention with substance abuse prevention and treatment and mental health services.

factors that influence decision-making about disease prevention, risk reduction and health promotion.

D. Ensure HIV Prevention Services Address Complex Issues that Increase Women of Color's Vulnerability for HIV

Federal, state and local HIV/AIDS funding agencies, private funders and HIV program managers must ensure that prevention services aimed at women of color address the situations that put women at risk, provide skills and tools to build self-esteem, and support safer sexual and needle-sharing practices. Interventions aimed at women of color must also address psychosocial issues related to self-esteem, feelings of powerlessness, domestic violence, sexual abuse and substance abuse. As appropriate for the particular sub-population, these programs must also integrate and reinforce substance abuse prevention and treatment.

E. Ensure HIV Prevention Programs Integrate Harm Reduction Strategies

Federal, state and local HIV/AIDS funding agencies, private funders and HIV program managers must ensure that prevention services aimed at women of color incorporate harm-reduction approaches for both sexual and drug-using behaviors that place women at risk for HIV infection. HIV prevention programs and policies must offer a wide range of options that will reduce sexual and drug-use-related risk for women in those instances where they cannot take all the steps necessary to protect themselves. These options include the development of effective, acceptable and available women-controlled barrier methods (such as microbicides), syringe availability, needle exchanges and women-centered substance treatment.

F. Ensure HIV Prevention Programs Address Complex Psychosocial-Economic Stressors

Federal, state and local HIV/AIDS funding agencies, private funders and HIV program managers must ensure that prevention services aimed at women of color address the socio-economic stressors they face. Programs must provide resources that will encourage women to participate in prevention interventions and motivate them to change their behaviors and maintain behavioral changes. Since many women at risk for HIV are substance users, interventions must integrate HIV prevention with substance abuse prevention and treatment and mental health services. Programs addressing homeless women and their families must also integrate HIV and substance abuse prevention and treatment, as well as mental health and primary health care services.

G. Ensure Delivery of Comprehensive HIV Care and Support Services

Federal, state and local HIV/AIDS funding agencies, private funders and HIV program managers must ensure that women of color living with HIV/AIDS receive comprehensive HIV health care and supportive services within a seamless environment, where services are co-located and are made accessible and available. These services should include HIV prevention and care services, substance abuse and mental health services, childcare and transportation. HIV service programs should offer appropriate linkages to family support services that can ease the burden of women living with HIV, including housing, nutritional assistance, respite care and in-home care, permanency planning and other child welfare services.

H. Ensure Delivery of Culturally Competent, Voluntary HIV Counseling and Testing and Early Intervention Services

Federal, state and local HIV/AIDS funding agencies, private funders and HIV program managers must ensure that women of color receive culturally competent, voluntary HIV counseling and testing and early intervention services. To encourage women at high risk of being infected with HIV to get tested, these services must include intensive outreach in settings where women of color go to receive other services such as substance abuse treatment, STD testing and treatment clinics; prenatal care clinics; family planning clinics; and family services and public assistance centers.

I. Ensure Delivery of Culturally Competent Health Care and Supportive Services

Federal, state and local HIV/AIDS funding agencies, private funders and HIV program managers must ensure that women of color living with HIV/AIDS receive culturally competent health care and supportive services. These services must be designed to take into account cultural norms, perceptions and beliefs about health and self-efficacy as a means of enhancing adherence to HIV treatment. Cultural factors impacting health-seeking behaviors, service utilization, provider-patient communications and health outcomes must also be integrated into service design and delivery.

J. Ensure Delivery of Substance Abuse and Mental Health Screening with Appropriate Referrals and Linkages to Related Services

Federal, state and local HIV/AIDS funding agencies, private funders and HIV program managers must ensure that women of color living with HIV/AIDS receive

substance abuse and mental health screening and are provided with appropriate referrals and linkages to related services as part of their HIV care. State and local jurisdictions should ensure that sufficient funding is made available for women-focused, culturally competent substance abuse and mental health treatment services.

K. Ensure Delivery of Bilingual and Bicultural Health Care and Supportive Services to Immigrant Women

Federal, state and local HIV/AIDS funding agencies, private funders and HIV program managers must ensure that immigrant women of color living with HIV/AIDS receive bilingual and bicultural health care and supportive services that are responsive to the social, economic and legal issues facing newly arrived immigrants. When bilingual services are not available, translation/interpretation services must be made available for women who do not speak English or have limited proficiency.

L. Ensure Delivery of Comprehensive and Coordinated Services for Rural and Homeless Women

Federal, state and local HIV/AIDS funding agencies, private funders and HIV program managers must ensure that programs aimed at rural and homeless women provide and coordinate a full spectrum of comprehensive HIV health care and supportive services. HIV service providers should work with other programs serving these special populations including rural and homeless health providers and homeless shelter providers to ensure that women living with HIV/AIDS are integrated into a comprehensive continuum of services.

IV. Key Findings: Barriers

The conference participants were divided into breakout groups based on race/ethnicity: African Americans, Latinas, Asians/Pacific Islanders and Native Americans. Each breakout group was asked to identify the barriers women of color face in accessing HIV prevention and care services based on their respective group's experience. The participants identified a host of factors that are specific to each ethnic/racial group as well as issues that cut across all or several groups. The cross-cutting barriers they identified have been grouped into the following major categories:

A. Inadequate Data Collection Systems

The participants observed that HIV/AIDS surveillance systems at the national level rely on data provided by the states, which are not uniform. In most instances information on race and ethnicity is limited to the five main racial and ethnic categories (i.e. white non-Hispanic, Black/African American, Hispanic/Latino, Asian/Pacific Islander and American Indian/Alaska Native/Native American). Some states only report racial and ethnic background for whites and African Americans, grouping cases from other ethnic/racial groups under "other" categories. For example Asians and Pacific Islanders in the U.S. represent close to 50 ethnic and national groups who speak more than 100 different languages, yet they are grouped together in national statistics as Asians/Pacific Islanders or subsumed by states into the "other category".

Data aggregated in this manner may mask important epidemiological variations based on national origin, geography and socio-demographic characteristics. Among Latinos, for example, injecting drug use plays a major role in fueling the

epidemic among Puerto Rican-born persons with AIDS in the Northeast and Puerto Rico, while for Latinos born in Mexico sexual transmission is the major mode of exposure for both men and women.¹³ Prevention and care services programs for Latina women in the Northeast that do not address substance abuse may, therefore, fail to provide key services for this sub-population.

Lack of demographic and HIV/AIDS surveillance and services utilization data on different ethnic and racial sub-populations, therefore, limits the effectiveness of planning and allocation of resources for prevention and care services programs.

Cultural competence requires that service providers learn new behavior patterns and apply that knowledge appropriately in cross-cultural transactions within the context of service delivery.

B. Lack of Tailoring

Programs and activities targeted at people of color in general and women of color in particular do not take into account the variations of socio-demographic characteristics, risk factors and health beliefs of the different ethnic and racial subpopulations. This lack of tailoring to address the specific needs of the various subpopulations creates barriers to services and impacts on the overall effectiveness of HIV prevention and care services.

C. Lack of Integration of Culture

In general, participants pointed out that the U.S. health care delivery system does not adequately incorporate knowledge of the cultural characteristics, values, norms, health beliefs and behaviors of different ethnic and racial sub-populations in the design and delivery of health care services. Culture refers to the integrated patterns of human behavior including thoughts, communications, actions, customs, beliefs, values and institutions characteristic of racial, ethnic, religious or social groups.¹⁴ Culture plays an important role in influencing health beliefs and behaviors. Women of color represent very diverse ethnic and racial sub-populations with variations in cultural values, norms and beliefs. These cultural variations are also reflected in differences among women of color in perceptions and beliefs about health, wellness, healing and disease and their causes; help-seeking and health-maintenance behaviors and practices; preferences in traditional and non-traditional approaches to health care; attitudes toward health care providers; and perceptions of the health care service delivery system in the U.S.

D. Lack of Cultural Competence

Participants repeatedly articulated that the lack of cultural competence in public health and health care delivery systems negatively impacts access to and utilization of health promotion and HIV prevention and care services by women of color. In this context, cultural competence is defined a set of congruent behaviors, attitudes and policies that come together in a system, agency or among professionals and enables that system, agency or those professionals to work effectively in cross-cultural situations.¹⁵ In the health care delivery arena cultural competence requires the integration and adaptation of knowledge about individuals and groups of people into specific standards, policies, practices and attitudes to increase the quality of services and produce better health outcomes.¹⁶ Participants also stressed that cultural competence goes beyond awareness, knowledge and sensitivity to cultural differences. Cultural competence requires that service providers learn new behavior patterns and apply that knowledge appropriately in cross-cultural transactions within the context of service delivery.

Effective communication between health care providers and patients is critical to the delivery of quality HIV care services. Participants indicated that many healthcare providers do not understand nor integrate knowledge of cultural differences when communicating with women of color. For example, many Asian women who have maintained traditional cultural values and norms may perceive their physicians as authority figures. Even in those instances when they do not fully understand the issues raised by a physician, they may not openly question their physician because of cultural constraints about challenging authority. In the context of communications regarding complicated HIV medication regimens health care providers, for example, may falsely assume that the women understand their instructions when they do not ask questions or sit in seemingly silent assent.

Participants also observed that lack of cultural competency has led to ineffective design and delivery of HIV prevention services. For example, some intervention strategies designed to increase protective behaviors among women at risk for heterosexually transmitted HIV have often failed to integrate knowledge and understanding of culturally mediated gender roles. These interventions have focused on factors such as perceived risk, HIV knowledge, self-efficacy and safer sex skills using individual cognitive-behavioral approaches. However, interventions that have not considered factors such as culturally prescribed gender roles, male attitudes towards safer sex, male violence against women, gender-based power inequities and socioeconomic dependency in creating HIV risk have missed the mark for women of color. For example Latinas and other women who have been socialized in traditional gender roles to be passive, submissive, complacent and dependent in their social interactions and sexual relations with men may have difficulty relating to risk-reduction interventions that stress sexual negotiation. Many women view sexual relations as an extension of emotional intimacy—something that happens without planning. Sexual negotiation also breaks with romantic notions of sexual relationships based on the spontaneity of the moment since it requires an analysis of how the sexual relations will be carried out.

Moreover negotiating condom use requires honest and open communication between sexual partners. Introduction of discussions regarding condom use by women in monogamous relationships for example may raise questions about their fidelity. In unequal relationships where men control the sexual transactions, attempts to negotiate safer sex could lead to conflicts and re-evaluation of the relationship and may place women at risk of physical and/or psychological abuse by their male partner.

E. Low Socioeconomic Status

Participants noted that a large proportion of women of color at high risk for HIV and living with HIV/AIDS have limited socioeconomic resources. These women are more likely to face unemployment or poverty, to live in inadequate or unstable housing or to be homeless. Faced with choices of feeding and housing their families and themselves or obtaining health care, women often place the needs of

their children and families first. Even when seeking care, they do not have sufficient resources to ensure that they and their families receive quality care.

F. Lack of Adequate Health Insurance Coverage

Participants identified lack of adequate health care coverage as a major barrier to access to quality HIV care. They observed that many women of color lack health insurance or have limited coverage and benefits and, therefore, lack access to adequate health promotion, disease prevention and health care services. Among adults living with HIV/AIDS, an estimated 55% are enrolled in Medicaid. Medicaid serves approximately 90% of the children with AIDS. However, ethnic and racial minority groups experience variations in health care coverage. About 23% of African Americans,¹⁷ 24% of Native Americans¹⁸ and 21% of Asian and Pacific Islanders¹⁹ are uninsured compared to 14% of whites. Latinos have the highest (37%) uninsured rates among all racial and ethnic groups in the U.S.²⁰ Medicaid provides an important safety net for ethnic and racial minority groups. About one-in-five (21%) African Americans, one-quarter (25%) Native Americans, 18% Latinos and 9% of Asian and Pacific Islander in the U.S. are covered by Medicaid.²¹

G. Impact of Welfare and Immigration Reform

Participants identified changes in welfare and immigration policies related to Medicaid eligibility as a barrier to access to care for many women of color who are immigrants. For example, a large proportion of Asians (66%) and Latinos (38%) in the U.S. are foreign born.²² In recent years the changes in Medicaid eligibility for legal immigrants have affected the enrollment of Latinos, Asians and Pacific Islanders and other immigrant populations in Medicaid. The number of Latinos covered by Medicaid for example decreased from 20% in 1994 to 16% in 1997. Many legal immigrants may fear that seeking Medicaid coverage for themselves or their children may place their immigrant status or future citizenship at risk.

H. Fragmentation of Services

Participants repeatedly identified fragmentation of services as a major obstacle to access to HIV prevention and care services for women of color. Although HIV prevention and care services may be available in some locales, health care and necessary social services are not uniformly available or accessible. Because of socioeconomic problems they face and the added weight of caregiving and family responsibilities, women of color require an added level of attention to be able to navigate the complexities of the health care and social services systems. The increased emphasis on managed care has exacerbated this problem, with health care providers limiting the type and duration of services that are made available. Women with HIV and multiple psycho-social needs may have to travel

to different service providers in different locations on different days to obtain such services as HIV primary care, substance abuse, mental health, housing, nutrition, day care and child welfare services. This fragmentation of services may also contribute to delays in accessing and utilizing HIV care.

I. Impact of Gender Roles

Participants identified culturally prescribed gender roles as a factor in access to and utilization of HIV prevention and care services. Cultural values, beliefs and norms influence gender roles among different sub-populations. Culturally prescribed gender roles may influence how women of color perceive themselves in intimate relationships, their role in the family, and their ability to have control over health care and social services. As prevention and care/service programs are developed and implemented, they must take into account the socio-cultural factors that influence gender roles among the diverse populations of women of color.

J. Racism and Discrimination

Participants noted that racism and discrimination also impact access to prevention and care services by women of color. Many women of color indicated that they often felt devalued and disrespected by service providers who were predominantly white because of their race/ethnicity, physical appearance, language spoken and accents, economic status and drug/alcohol dependencies. They also indicated that the quality of care they received depended on the location of the services. They perceived services received in locations in their own neighborhoods to be of less quality than those in predominantly white areas.

A growing body of research reports that racial disparities in health status can be explained, at least in part, by racism and discrimination within the health care system itself. A survey conducted by the Kaiser Family Foundation in 1999, found that 64% of African Americans and 56% of Latinos believe they receive lower quality health care than whites. The survey also showed that 35% of African Americans and 36% of Latinos said that they, a family member or friend had been treated unfairly specifically because of their race or ethnicity when seeking medical care, compared to 15% of whites. Moreover 14% of Latinos felt they have been judged unfairly or treated with disrespect because of how well they speak English, compared to 1% of whites.²³

K. Lack of Political Clout

Participants highlighted lack of political power as a major obstacle to increasing access to quality HIV prevention and care services for women of color. Many of the structural, social, cultural, economic and psychological issues described above

limit the ability of women of color at risk for or living with HIV/AIDS to engage in effective advocacy with local and state decision-makers, HIV/AIDS planning bodies, established AIDS service organizations and AIDS activists. In some instances, women of color have been excluded from participating in HIV prevention and care/service decision-making processes at the state and local levels (HIV Prevention Community Planning Groups and Title I Ryan White Planning Councils and Title II Consortia). When included in these planning bodies many women of color indicated they felt “tokenized” and unprepared to participate effectively in the planning and decision-making processes.

The women identified the following as factors affecting their participation: meetings scheduled at inconvenient locations or times, lack of support for transportation and child care, and lack of knowledge and insufficient orientation regarding terminology used, roles and responsibilities, decision-making procedures and planning, and allocations or priority setting processes. Due to the barriers encountered women of color have not been able to be as effective in advocating for their own needs with policy makers or in the general HIV/AIDS advocacy community.

V. Recommendations

A. Develop and Implement Policies and Mechanisms to Facilitate Meaningful Participation of Women of Color in HIV Policy and Decision-Making Bodies

The participants stressed the need for women to participate in the policy decision-making process at the federal, state and local levels. Women of color must be included in HIV Prevention Planning Groups and Ryan White Planning Councils and Consortia. To address this, state and local governments and planning bodies must develop policies and allocate resources to ensure the recruitment and retention of women of color and provide on-going orientation, training, support and mentoring for women to have meaningful participation in planning bodies.

B. Ensure Delivery of Integrated and Comprehensive Services for Women

Participants also stressed that programs for women of color would have to tackle the psychosocial and systemic barriers discussed above in order to effectively address their needs. Programs aimed at women of color have to integrate a comprehensive array of health care and supportive services that specifically address the cultural, linguistic and socioeconomic barriers faced by women. This requires federal, state and local funding agencies to set standards and provide technical assistance to service providers to ensure that services are delivered within a culturally competent framework. Culturally competent service delivery requires integration of knowledge and understanding of the language and socio-cultural background of different sub-populations of women of color, their families and their living environments into the policies, structures and practices of the organizations.

This must be done by first acknowledging that women of color at risk for HIV or living with HIV/AIDS have historically been under-served by the health care system because of gender insensitivity, racism, cultural and linguistic barriers and the complexity and fragmentation of the health care system. It also requires an examination of existing service delivery structures to identify systemic barriers to culturally competent service delivery. Finally managers of HIV prevention and care programs must be proactive in integrating cultural competence into the design, implementation and operation of programs aimed at women of color.

i. HIV Prevention

HIV prevention interventions must take into account the culture of the women being addressed and how culture impacts perceptions about sexuality, gender roles, self-worth, self-efficacy and interpersonal relationships. This means that interventions targeted to African Americans, Asians/Pacific Islanders, Latinas and Native Americans must incorporate the cultural variations found within each sub-population of women. The messages and interventions must provide a context that reflects and relates to the realities faced by women in their personal lives and address the many factors that influence decision-making about disease prevention and health promotion.

The interventions aimed at women of color must be linguistically specific and gender, developmentally and culturally appropriate. These services must clearly address situations that put women at risk and provide skills and tools to build self-esteem and support safer sexual and needle-sharing practices. As appropriate for the particular sub-population, these programs must also integrate and reinforce substance abuse prevention and treatment. Interventions aimed at women of color must also address psychosocial issues related to self-esteem, feelings of powerlessness, domestic violence, sexual abuse and substance abuse.

Harm Reduction: HIV prevention programs must meet the needs of women where they are in their individual lives. HIV prevention programs and policies must offer a wide range of options that will reduce sexual and drug use related risk for women in those instances where they cannot take all the steps necessary to protect themselves. The development of effective, acceptable and available, women-controlled barrier methods such as microbicides, for example, is essential to provide women with viable options to risk reduction. Options such as syringe availability, needle exchange and women-centered substance treatment must be made available for women who are at risk for HIV infection due to injection drug use. Programs that stress total compliance with behavior change strategies may not fit the needs of women of color and must provide other options that reduce risk in those instances.

Life Situation: Because many women at high risk for HIV come from limited economic means, programs must provide resources that will encourage women to participate in prevention interventions and motivate them to change their behaviors and maintain behavioral changes. As many women at high risk for HIV are substance users, HIV prevention, substance abuse prevention and treatment and mental health programs must work hand-in-hand to prevent HIV transmission and substance abuse. Programs should also integrate and provide substance abuse treatment and mental health services when necessary. As the number of homeless women and families continues to increase, homeless programs must address the HIV prevention and care, as well as the substance abuse and mental health service needs of homeless women.

Gender Roles: HIV prevention programs aimed at women must take into account the woman's perceived gender role and how that impacts her interpersonal relationships. Delivering messages that do not place women in the context of their sexual and romantic relationships will not effectively address those behaviors that place women at risk. Programs for women should take steps to address how gender roles impact their self-efficacy about preventing HIV transmission. For example, interventions for women of color must address the power dynamics in sexual relationships between women and men of color, including culturally defined gender roles that prevent women from objecting to risky sexual behaviors and subordinate relationships that place women at risk for domestic violence.

Stage of Development: HIV prevention programs must be designed to address the needs of women based on their stage of development and address women across their life cycle. Special attention must be aimed at developing prevention interventions that are appropriate for young women, women of childbearing age and women over 50 years of age. Programming aimed at young women of color, for example, must take into account the specific needs of young people, including integrating job training, career counseling, drop-out prevention, pregnancy prevention and parenting training into educational programs.

ii. HIV Care/Services

Program Integration: HIV prevention and care/service activities should not be carried out in isolation from other programs and services that women may need to lead healthy lives. Primary among these are substance abuse and mental health services, family support services, childcare and transportation. HIV care/services programs should include appropriate linkages to family support services that can ease the burden of women living with HIV, including housing, nutritional assistance, respite care and in-home care, as well as child welfare services. Because of the combination of need, lack of resources, family obligations and service fragmentation, programs for women must be provided in a seamless environment, where services are co-located and are made accessible and available.

Early Intervention: Additional efforts must be made to encourage women at high risk to get tested for HIV. Because women historically have entered treatment late, their longevity after diagnosis has been much shorter than for men. Women of color who access substance abuse treatment, STD testing, prenatal care, family services and public assistance must be provided with HIV education at these service sites. Women who visit service delivery sites should be encouraged to seek voluntary HIV testing and to enter into treatment if they are HIV positive.

Culturally Competent Programming: Although service delivery programs have health outcomes as their primary goal, program design should also take

into account cultural perceptions about health and self-efficacy as a means of enhancing adherence to HIV treatment and other factors that impact on health seeking behavior, service utilization and health outcomes—including longevity and hospitalizations. Programs for women of color living with HIV should take steps to address how culture, language, perceptions of self-worth, self-efficacy and gender roles impact improving and maintaining their health status. Primary among these steps is for health care and supportive services providers to develop a relationship of trust with women and to ensure that women feel empowered to ask questions and raise their own issues regarding their needs and how available services are addressing them.

Integration of Substance Abuse and Mental Health: Because of the large number of women of color living with HIV/AIDS in need of substance abuse and mental health services, women seeking HIV care and services should be routinely screened for substance abuse and mental health treatment. Health care providers should refer women in need of treatment to facilities that provide both substance abuse and mental health services. State and local jurisdictions should ensure that sufficient funding is made available to provide these concurrent services. Substance abuse and mental health services should take into account cultural characteristics of women and their life situations. For example, if women have small children and must enter in-patient substance abuse treatment, allowances must be made for their children to be housed with their mothers.

Immigrant Women: Services for recent immigrants must take into account the culture of the women and be sensitive to the lack of familiarity of the women with clinical services in the United States. Bilingual and bicultural service providers should be available in service sites reaching this population, and when these are not available, translation services must be available for women for whom English is not their first language.

Rural and Homeless Women: Programs aimed at rural and homeless women of color must coordinate a full spectrum of services, especially continuity of care for women who need assistance taking their medication. HIV care/service providers must strive to create networks of physicians, homeless shelter providers, rural care/service providers and others to work in concert to ensure women are integrated into a continuum of services.

VI. Background

Between 1981 and the end of 1999, a total of 733,374 AIDS cases were reported to the Centers for Disease Control and Prevention (CDC).²⁴ Of these cases, 82% were men, 18% were women, and 1% were children less than 13 years of age. The cases were distributed among transmission categories as follows: 47% in men who have sex with men, 25% in injection drug users, 10% in persons infected heterosexually, and 2% in persons infected through blood or blood products.

Ethnic and racial minorities in the U.S. have been disproportionately impacted by HIV/AIDS since the onset of the epidemic. By the end of 1999 people of color represented more than 56% of the cumulative AIDS cases in this country: African Americans 37%; Latinos 18%; Asian/Pacific Islanders <1% and Native Americans <1%.²⁵ During the 1990s the disproportionate impact of HIV/AIDS on people of color continued to increase, and today people of color represent the majority of new AIDS cases and of people living with HIV/AIDS. African Americans and Latinos are the most severely impacted groups among people of color.

A. African Americans

According to the CDC, African Americans have outnumbered whites in new AIDS diagnoses and deaths since 1996 and in the number of persons living with AIDS since 1998. African Americans represented nearly half (47%) of the 46,400 new AIDS cases reported in 1999. Among males, African Americans made up 42% of the new AIDS cases in that year compared to whites that accounted for 36% of these cases. Nearly two-thirds (63%) of all women reported with AIDS in that year were African American. The pattern was mirrored for African American children who represented close to two-thirds (65%) of all reported pediatric AIDS cases in 1999. The impact of AIDS among African American adults/adolescents is most dramatically reflected in the 1999 AIDS case incidence rate for this group: 84.2 per 100,000, population. This was more than two times greater than the rate for Latinos and 9 times greater than the rate for whites. In 1993, there were an estimated 60,649 African Americans living with AIDS in the U.S. By 1998 this number had increased to 117,890—an increase of 94%. African Americans accounted for 49% of the estimated 17,840 deaths of persons with AIDS in 1998, while whites accounted for 32% of the estimated deaths in the same year.²⁶

B. Latinos

In 1999, Latinos—including residents of Puerto Rico—accounted for 13% of the U.S. population and 19% of the total new AIDS cases reported that year. Among males, Latinos accounted for 20% of the new AIDS cases reported in the same

year. Latinas accounted for 18% of the new AIDS cases reported among women, and Latino children made up 21% of the new pediatric cases reported in 1999. The AIDS incidence rate per 100,000 population among Latino adults/adolescents in 1999 was 34.6, close to four times the rate for whites, nine per 100,000. In 1993, there were an estimated 31,209 Latinos living with AIDS, while in 1998 the estimated number increased to 57,722—an increase of 85%. Latinos accounted for 18% of the estimated deaths due to AIDS in 1998.²⁷

C. Asians and Pacific Islanders

In 1999, Asians and Pacific Islanders (APIs) accounted for 4% of the U.S. population and approximately 1.4% of the cumulative AIDS cases.²⁸ APIs also accounted for 0.8% of the new AIDS cases reported in 1999. APIs accounted for 0.9% of the new AIDS cases reported among men, 0.6% of the new cases reported among women and 0.8% of the new pediatric AIDS cases reported in the same year. Males made up close to 83% of the new AIDS cases reported among APIs in 1999 and females made up 17% of the cases. By exposure category, men who have sex with men made up 64%, and heterosexual contact accounted for 9% of the cases among API adults and adolescents in 1999. The AIDS incidence rate per 100,000 population among API adults/adolescents in 1999 was 4.3. In 1993, there were an estimated 1,288 APIs living with AIDS while in 1998 the estimated number rose to 2,324—an increase of 80%. APIs accounted for 0.6% of the estimated deaths due to AIDS in 1998.²⁹

While the impact of HIV/AIDS among this population appears to be relatively low compared to other ethnic/racial minority groups, the current system of health data collection and surveillance does not give us a true picture of the nature and trends in the HIV/AIDS epidemic among APIs. The API population is the fastest growing ethnic/racial population in the United States. According to the U.S. Census Bureau, the API population in the United States increased 95% and another 43% from 1990 to 1999.³⁰ This population is also very diverse, relatively young and has a high proportion of foreign-born persons. However, many states continue to report HIV/AIDS data for APIs under an “other” category, and few states disaggregate API data by ethnicities/national origins. Furthermore, national data obscures the differences in trends among the diverse API sub-populations by ethnicity/national origin and region.

D. Native Americans

In 1999, Native Americans accounted for about 1% of the U.S. population and approximately 0.3% of the cumulative AIDS cases.³¹ In terms of new AIDS cases reported in that year, Native American accounted for 0.4% of these cases reported. . Native Americans accounted for 0.3% of the new AIDS cases reported among men,

0.4% of the cases reported among women and 0.8% of the pediatric AIDS cases reported in 1999. Males made up close to 76% of the new AIDS cases reported among Native Americans in 1999, and females made up 22% of the cases. By exposure category, men who have sex with men made up 36%, injection drug use 19% and heterosexual contact 9% of the cases among Native American adults/adolescents in 1999. The AIDS incidence rate per 100,000 population among Native Americans adults/ adolescents was 11.3 in 1999 –1.25 times the rate for whites. In 1993, there were an estimated 566 Native Americans living with AIDS, while in 1998 the estimated number rose to 978—an increase of 73%. Native Americans accounted for 0.4% of the estimated deaths of person due to AIDS in 1998.³²

Compared to African Americans and Latinos, the trends of HIV/AIDS among Native Americans appear to be relatively low. However many experts agree that the number of AIDS and HIV cases among Native Americans is higher than what has been reported to the CDC due to misclassification of the ethnicity of Native Americans by health workers and officials as either white, Hispanic or Asian.³³ In addition it is important to look at the unique features of HIV/AIDS among this population. For example, approximately half of the Native American population lives on or near reservations; the other half resides in other rural areas and in urban areas. Compared to the total number of person living with AIDS in the United States, a higher proportion of Native Americans with AIDS resided in rural areas.³⁴ Compared to the general U.S. population the Native American population is relatively young.³⁵ Moreover a higher proportion of the AIDS cases among Native Americans were among people aged 20 to 29 when compared to the total U.S. cases in the same age group (23% versus 17%, respectively).³⁶

VII. Recommendations by Breakout Groups

A. African American Breakout Groups

i. Include Women in Policy Development and Decision-making Processes

Participants emphasized the need to include African American women in the policy decision-making process at the national, state and local levels. They underscored the importance of assuring the input of African American women in the development of HIV-related policies and prevention and care programs that are designed to address their needs. They also stressed the need for federal, state and local governments to fund training, technical assistance, mentoring and support to increase decision-making bodies such as prevention community planning groups, community advisory boards, HIV planning councils and consortia.

ii. Support Tailored, Culturally Competent HIV Prevention and Care Programs

a. Address Socio-cultural and Economic Factors

Participants recommended that prevention and care programs targeted to African American women and other women of African descent take into account the social, cultural and economic factors that contribute to their risk for HIV infection and impact their utilization of health care services. They identified such factors as the impact of poverty, racism and discrimination on access to health promotion and health care services; economic dependence on male partners; domestic violence, and mental health and substance abuse issues.

The participants articulated the importance of addressing HIV prevention and care service delivery within the context of the specific life situations of the African American and women of African descent to be reached. For example to effectively reach women with limited economic resources who are heads of households and the primary caretakers and care givers within their families, it is critical for HIV prevention and care programs to also address their basic needs and link them to appropriate services and resources. HIV prevention and care programs must provide childcare; transportation; and links to income support, housing and nutrition services.

They stressed the need for tailoring programs to address the variations in the life experiences of different sub-populations of the women to be

reached. The participants also stressed the importance of developing and implementing culturally competent prevention and care delivery strategies and interventions that take into account the role of cultural and socioeconomic factors in fostering health beliefs, perceptions of self-efficacy, lifestyles, risk behaviors, behavioral change and utilization of health care services.

b. Recognize and Address Culturally Defined Gender Roles

In addition, the participants identified culturally defined gender roles that influence the dynamics of male-female sexual relationships. They also identified sexism and misogyny as factors that impact women's ability to take control of their sexual decision making and health care. The participants highlighted the variations in culturally defined gender roles depending on the age, class, geographic residence and national origin of the women to be reached. For example, young African American women who have been socialized within "hip-hop" culture will have different perceptions of their relationship to men and their ability to control sexual decision making than recently arrived young women of African descent from the Caribbean.

c. Integrate Mental Health and Substance Abuse Prevention and Treatment

Taking into account the various life stressors faced by many African American women and women of African descent, as well as the significant role substance abuse plays in HIV transmission, the participants also emphasized the importance of linking HIV prevention and care services with mental health and substance abuse prevention and treatment services. In addition the participants recommended that programs and services targeted to African American women and women of African descent integrate wellness models.

Participants also noted programs need to provide support and counseling to HIV positive women so that they can disclose their status to their children and families and deal with the consequences of such disclosures.

d. Support Outreach in Venues Where Women Are

Participants stressed the importance of providing outreach and peer educational services to women in the venues where women are likely to be found. For example, they recommended that outreach workers and peer educators be based in private physicians' offices to reach out to women and provide them with HIV/AIDS education. They also identified the key role the church plays in the lives of African American women and urged greater emphasis on involving faith-based organizations in HIV/AIDS prevention and care programs targeted to women. They recommended education of pastors and faith leaders to engage churches in community

outreach and HIV/AIDS education. They also recommended integration of HIV/AIDS outreach and education in health fairs and during youth basketball/football games.

iii. Support Integrated One Stop Service Delivery

Participants discussed the barriers to access created by the design and delivery of HIV prevention and care services. They said that most clinics and service agencies are open on a 9-to-5 schedule. They indicated that services for poor women and particularly African American and women of African descent are often provided at inconvenient times and venues. Some women indicated that there is a false assumption made by service providers that most African American and women of African descent don't work. They are often given appointments during their hours of work and are unable to keep them because they do not get paid time off from work for medical appointments or are afraid that taking time off frequently for medical appointments may lead to disclosure of their HIV status.

Other women indicated that services are set up at times and places that are inconvenient due to their family and childcare responsibilities. They felt that service providers falsely assume they are at home all day doing nothing. Many women identified problems in juggling and keeping multiple appointments given to them on different days, times and locations for themselves and their children. Many women stated that they have to travel long distance, even within their own cities, to get care and services because many safety-net hospitals and clinics are closing down in their neighborhoods.

All participants stressed the importance of setting up integrated services in one place that could be available for them and their families/children in a location close to where they live. They basically called for one-stop service delivery with flexible hours that considered their family and/or work responsibilities.

The participants also recommended streamlining and integrating applications for various medical and psychosocial support services into a unified application to cut down on duplication and multiple application, eligibility, certification and enrollment processes.

Young African American women who have been socialized within "hip-hop" culture will have different perceptions of their relationship to men and their ability to control sexual decision making than recently arrived young women of African descent from the Caribbean.

They also noted that many programs provided case-management services and that while these services are needed and important to coordinate their services there is often duplication and lack of coordination when a client has more than one case manager. The participants recommended that programs provide trained case managers and that case-management services be coordinated and centralized.

The participants also stressed the importance of incorporating and offering holistic treatment options including acupuncture, herbal medicine and other “alternative” treatments.

The participants underscored the need to integrate good gynecological and reproductive health services into HIV care and also underscored the need to have access to trained and experienced infectious disease doctors as well as nurse practitioners and other health professionals who are knowledgeable about HIV and its impact on women.

iv. Support Cultural Competency Training for Health Care Providers

The participants recognized that many service providers lack knowledge and understanding of their life situations, culture and the impact of social and economic factors on their response to health care services. Many women stated that they have experienced racism in receiving services from ASOs and clinics. They also articulated their perceptions that many providers have biases and make false assumptions about them based on their race and class status. Others discussed a lack of trust in the health care system due to the legacy of the Tuskegee Syphilis study.³⁷

The participants recommended that federal, state and local funding agencies require and support cultural competency training for health care providers (including doctors) and staff of ASOs in order to improve the quality of services they provide, improve doctor-patient communications and increase their trust in the health and human service delivery system.

v. Address the Needs of Special Populations

a. Young Women

Given the increasing rates of HIV infection and AIDS among adolescent and young African American women and other women of African descent, the participants recommended a special focus on the unique needs of young women. They recommended that HIV prevention and care programs for this population be coordinated with sexuality education, teen pregnancy prevention programs, parenting skills training, substance abuse prevention and treatment, and job training and career counseling services.

Services such as transportation, childcare and other supportive services should also be part of the package of services offered to this population. The participants identified the need for more trained HIV-knowledgeable adolescent care physicians. They also indicated that targeted outreach to engage young people be done by trained peer educators and outreach workers who understand and can effectively communicate with adolescents and young adults.

The participants also noted that prevention and care programs for adolescents and young adults must be developmentally and culturally appropriate for these age groups and provided in the vernacular language that they speak.

The participants observed that many programs focus on pregnant adolescents and young women but do not address the specific needs of the young men these women are involved with. They recommended that programs targeted to heterosexual female adolescents and young women also take into account their relationships with men and address their needs regarding HIV prevention and care services as well.

Finally the participants noted that stigma plays a significant role in the response to HIV/AIDS among female adolescents and young women. Strategies to deal with HIV-related stigma, to reduce its deleterious impact and to assure confidentiality must be integrated into HIV prevention and care programs targeted to these populations.

b. Women in Rural Communities

The participants recognized the growing rates of HIV infection and AIDS among women in rural areas and women living in the Southern Belt states. They identified the need to develop targeted and tailored HIV-prevention and care programs for women living in rural communities where there is a lack of trained health care professionals who are knowledgeable regarding HIV/AIDS prevention and care and a lack of support services and programs for women at risk and those living with HIV/AIDS.

Transportation services to increase access to health care providers and services in rural and isolated communities were also identified as a critical need. Some recommended the use of mobile health vans that are not labeled “HIV/AIDS” to provide an array of health services including but not limited to HIV. The participants stressed the importance of developing strategies to address HIV-related stigma and confidentiality concerns in these communities.

Participants also stressed the importance of developing programs and services that match the realities of life in rural areas and warned against cookie-cutter approaches that copy programs that work in urban areas to rural settings.

c. *Homeless Women*

The participants discussed the high rates of homelessness experienced by African American women and other women of African descent. They agreed that HIV prevention and care programs must address the needs of this vulnerable population by addressing their multiple psychosocial and economic needs. Linkages to housing, family-centered, childcare, mental health, substance abuse prevention and treatment, domestic violence, family planning, reproductive health, parenting support and transportation services were identified as a key components of effective HIV prevention and care programming for this population.

d. *Immigrant Women*

Participants noted that there is a large population of women of African descent in the U.S. who do not identify as "African American" such as Haitians, Africans, and West Indians who are immigrants and need services that address their immigrant status. HIV prevention and care programs must address the needs of both documented and undocumented immigrants. Some of the barriers to prevention and care services for these populations include HIV-related stigma; fear of disclosure of their HIV status and of jeopardizing their residency status; cultural differences related to health beliefs, wellness and utilization of health care; gender roles; lack of health care coverage; and low income.

vi. Develop Mutual Support Networks and Mechanisms for Empowerment

The participants emphasized the importance of developing and maintaining mutual support networks for women to assist in building their self-esteem and encouraging them to adopt and sustain risk reduction and health promoting behaviors. They stressed the importance of promoting a sense of sisterhood among women to provide emotional support and guidance through on-going group meetings in a safe place to share their "secrets" and examine the psycho-social and emotional baggage that contributes to low self esteem. Such mutual support networks could also serve as a vehicle to allow women to share their day-to-day struggles to survive, deal with their sense of self worth, explore their historical and cultural roots, and reaffirm their sense of personhood and community.

The participants also expressed their sense that volunteer peer educators were often exploited by AIDS service organizations (ASOs) and services. They felt strongly that outreach workers and peer educators provide a valuable service and should be paid for their work. They stated that paid work also helped women to increase their sense of self-worth and self-sufficiency. Acknowledging their value by paying them for the services they provided also served to build their self-esteem and empower women.

Participants also noted that ASO staff often create competitive situations for women living with HIV/AIDS who serve on program or community advisory boards by dispensing special privileges to some and not to others. These situations are counter-productive and undermine the development of mutual support and mentoring mechanisms for women living with HIV/AIDS. The participants stressed how important it is for ASO providers to recognize that while women need help, they also need the opportunities and vehicles to help themselves.

vii. Foster Collaboration and Eliminate Duplication of Services

The participants discussed the competition for funding among community-based organizations (CBOs) in communities and noted the difficulties smaller CBOs, particularly minority ones have in accessing funding from federal, state and local sources. They recommended that funding sources encourage and facilitate collaboration among service providers that would be mutually beneficial for the organizations and also strengthen the network and quality of services available for affected women and women living with HIV/AIDS. Fostering collaboration among organizations and service providers could also serve to eliminate duplication of services and to fill gaps in needed services.

viii. Support Tailored Behavioral, Clinical and Service/Treatment Utilization Research

Finally the participants identified the need to conduct more tailored behavioral, clinical and service/treatment utilization research focused on the various sub-populations of African American women and other women of African descent. This research would identify the specific factors that place women at increased risk for HIV infection; define the impact of racism/discrimination and self-esteem on vulnerability to HIV infection and utilization of health care services; develop effective, culturally competent prevention interventions; and identify barriers to adherence to HIV/AIDS drug treatment and healthcare regimens and strategies to increase and support adherence.

B. Hispanic/Latina Breakout Groups

i. Include Women in Policy Development and Decision-making Processes

The participants identified the lack of adequate representation of Hispanic/Latina women in HIV policy-making bodies. They recommended that federal, state and local funding agencies increase their efforts to assure adequate representation of Hispanic/Latina women in decision-making and policy development processes related to HIV/AIDS such as prevention community planning groups, community advisory boards, HIV planning councils and consortia. The participants also stressed the need for funding to support training, technical assistance and support/mentoring programs to assure meaningful inclusion and participation of Hispanic/Latina women in the policy-making process at all levels. They recommended that federal, state and local government provide resources, support and information for Latina women to be effective advocates and accountable to their communities.

The participants also indicated that the Centers for Disease Control and Prevention (CDC) should step up their efforts to assure that state and local health departments are effectively implementing the principles of parity, inclusion and representation in the HIV Prevention Community Planning Process. They felt that these principles are not adequately adhered to on community planning groups and that the lack of compliance limits the ability of Hispanic/Latina women to provide their input on priority setting for culturally competent HIV prevention interventions; voluntary HIV counseling, testing and referral; partner counseling; and referral services tailored to their communities.

ii. Improve Data Collection, Surveillance and AIDS/ HIV Reporting Systems

The participants identified the problems related to use of data for program planning and resource allocation particularly when there is no standard requirement to collect HIV/AIDS data by race/ethnicity and the national origin of Hispanic/Latino sub-populations. They recommended that federal, state and local agencies develop standardized data collection systems that include disaggregated data on Hispanic/Latinos by national origin (Mexican, Puerto Rican, Cuban, Dominican, etc.), gender and mode of transmission. Such data would enable more effective and targeted program development and resource allocation to different Hispanic/Latino sub-populations based on the trends in HIV and AIDS specific to sub-group.

The participants also noted that the CDC does not collect any data on female-to-female transmission of HIV. They recommended that HIV surveillance reports include data on the actual number of cases of HIV infection among lesbians and

male to female transgendered persons in order to gauge the need for services and plan interventions for these populations.

iii. Support Tailored, Culturally Competent HIV Prevention and Care Program

a. Recognize and Address Socio-cultural and Economic Factors

The participants identified the socio-cultural and economic factors that increase vulnerability for HIV infection and impact access to care for Hispanic/Latina women. They recommended the development of comprehensive culturally competent HIV prevention and care programs that integrate substance abuse prevention and treatment with domestic violence prevention and support services. They recognized that many Hispanic /Latina women are monolingual in Spanish or have limited English proficiency (LEP) and need services provided in their own language or through trained interpreters or translators. Participants also noted that HIV care and treatment services must also make complementary therapies (acupuncture, herbal medicine, etc.) available to them.

The participants stressed the importance of promoting, supporting and funding the dissemination information to service providers on prevention and intervention strategies that have been tested, evaluated and proven to be effective among different sub-populations of Hispanic/Latina women that are not only limited to promotion of condom use.

b. Understand and Address Culturally Defined Gender Roles

Participants observed that many Hispanic/Latina women are socialized into culturally prescribed gender roles that promote male dominance and superiority and female submissiveness and inferiority in sexual and interpersonal relationships. There are variations by sub-group by national origin, class and level of acculturation on the degree to which Hispanic/Latina women adhere to these gender roles and on women's perception of their status and equality in relation to men. Despite these variations, the vestiges of culturally defined gender roles still play an important role in increasing their vulnerability for HIV infection.

While homosexuality, bisexuality and drug use exist, strong cultural taboos regarding bisexuality, homosexuality and drug use serve to increase Hispanic/Latina women's denial and lack of awareness of the possibility that their partners are engaging in risky sexual and/or drug using behaviors. Moreover since HIV was initially reported in gay/bisexual men and injection drug users, many women in monogamous relationships may not perceive that they are at risk through sexual contact with their male partners.

Traditional cultural roles also promote passivity and submissiveness to the male in sexual relationships and leave women unprepared to negotiate safer sex or insist on condom use by their male partners. Romantic love and sexual relationships are often blended into one concept and many women believe that sex equals love.

Insisting on safer sex behaviors may raise issues about their fidelity and may place some women at risk of domestic violence. Moreover, for many Latinas, womanhood is defined by their ability to procreate. The use of condoms may prohibit procreation and may also imply promiscuity.

Many women are unfamiliar with their bodies and cannot talk openly about their female genitalia nor their sexual needs and feelings. Discussion of sexuality and sexual relationships is also considered taboo. Because of the variations in cultural values and norms by national origin, class, level of acculturation and literacy there are also variations by sub-groups in what is considered acceptable language in English or Spanish regarding sex and sexuality.

Participants also noted that special focus must be placed on reaching the transgendered women who often face isolation, ostracism and exploitation due to culturally prescribed gender roles.

Young women are another population needing special focus because of the sexual harassment and exploitation they may experience at the hands of men who are older than them. The participants stressed the importance of **targeting and providing educational interventions for heterosexual men** as part of prevention efforts aimed at reducing heterosexual HIV infection among women.

The participants also noted that service providers must integrate knowledge of the impact of culturally prescribed gender roles on HIV risk in the design of HIV prevention interventions targeted to Hispanic/Latina women. These interventions must also be tailored to the specific Hispanic/Latino sub-group, taking into account national origin, class, age and literacy and acculturation levels of the targeted women.

c. Address Racism and Discrimination

Participants noted that Hispanic/Latina women often experience racism, classism and discrimination when accessing health care services. They noted that providers' attitudes towards them are colored with racism and that they feel they are treated differently because they are poor, are immigrants or do not speak English fluently or at all. In order to address providers' attitudes, biases and practices, participants recommended cultural competency and diversity training for HIV prevention and care providers including physicians and other health care professionals.

d. *Integrate Substance Abuse Prevention and Treatment*

Participants discussed the key role that substance abuse plays in fueling the HIV epidemic among Hispanic/Latina women and stressed the importance of integrating substance abuse prevention and care services within HIV prevention and care programs. Harm reduction strategies including needle exchange and syringe availability programs were identified as a key component of prevention services for women who inject illicit drugs. They also recommended the expansion of women-focused drug treatment services including methadone treatment and highlighted the need for more residential drug treatment beds for female adolescents and women.

The participants stressed the importance of expanding treatment capacity and programs specifically designed to meet the developmental needs of female adolescents. They felt strongly that adolescents should not be placed in adult treatment facilities. Finally they articulated the need to expand residential drug treatment facilities that address the specific needs of women with children and strongly advocated for changes in policies regarding cut-off ages for the inclusion of women's children in residential treatment programs. Participants also noted the need to expand the available transitional homes for both female adolescents and women.

e. *Support Outreach, Referral and Linkage and Prevention Case-Management Services*

The participants also recommended that HIV prevention programs include intensive outreach services and referral and linkage to available resources and services such as primary care, case management, entitlements, substance abuse treatment, mental health services, family services, transportation, food and nutrition services, childcare, medication assistance, housing, reproductive health and prenatal care services.

Participants noted that prevention case-management services aimed at women with entrenched psycho-social problems and needs should be more widely offered as part of the continuum of HIV prevention services by staff trained in this approach.

f. *Promote Voluntary HIV Counseling, Testing and Partner Notification*

They also recommended that voluntary HIV counseling and testing services be integrated into other service venues for women such as family planning clinics, WIC centers, public assistance offices, drug treatment programs, etc. The counseling and testing services should be offered as part of comprehensive services for women that are flexible and responsive to their multiple needs. HIV counseling and testing services must also provide referral and linkage to primary care and other psychosocial and

supportive services as noted above. New testing technologies including rapid testing should be made available to increase access to these services and increase the number of women learning their HIV test results and being linked to necessary services.

Participants also noted the movement to mandate partner notification on a national and state level and stressed the importance of offering voluntary partner notification services to women. The potential for violence against women by male partners was raised as an important issue to consider in planning and delivering partner notification services.

These services should be provided by trained culturally competent service providers who understand the life situations and culture of the women being targeted and can deliver the services in the women's primary language. All forms including informed consent forms should be available in both English and Spanish at a reading level that is comprehensible to the women. In the case of women who are not literate in English or Spanish, service providers who speak their language should accurately explain the content of the forms to them. The participants also stressed the need to develop and integrate more non-literacy based educational approaches that use the broadcast and visual media, (audio and video tapes, symbols, murals and pins) to provide information and convey important prevention and care messages.

g. Support and Promote Peer-Led Interventions

Participants discussed the key role of peer-led HIV prevention and treatment education interventions in providing services to Hispanic/Latina women. They recommended that funding sources place greater emphasis on providing funding and support for the training of peer educators and for programs to employ bilingual/bicultural peer educators. They cited numerous examples of the effectiveness of peer-led models as a mechanism to reach and engage Hispanic /Latina women in HIV prevention and care services. Participants pointed to the "Promotoras" model of health education used in the barrios and "colonias" of the Southwestern and border-states as an example of strategies that work among Hispanic/Latinas. They also pointed out that peer-led models work effectively among adolescents and young women as well as incarcerated women.

h. Integrate Quality Assurance Mechanisms and Monitoring

The participants recommended that funding sources require and support the implementation of comprehensive quality assurance mechanisms by all service providers in order to evaluate and monitor the quality, access, availability and cultural competence of HIV prevention and care services targeted to and delivered to Hispanic/Latina women, including those of limited English proficiency (LEP).

iv. Encourage and Support Collaboration

The participants stressed the importance of collaboration among service providers to assure the availability of a comprehensive network and continuum of HIV prevention and care services for Hispanic/Latina women. The participants stressed that these services must be provided using holistic models that are culturally competent, age and language appropriate and address the needs of different sub-populations of Hispanic/Latina women regardless of their immigration or citizenship status.

v. Promote Empowerment and Foster Sisterhood Among Women of Color

Participants stressed the importance of integrating HIV prevention and care strategies that promote the empowerment of women of color. Such strategies should focus on building self-esteem and developing knowledge and skills to enable women to adopt and maintain risk-reduction behaviors, manage and control their sexual decision-making and make informed decisions related to their HIV care. The participants also recommended the integration of empowerment strategies as part of HIV prevention and care services that serve to assist women to gain the tools and resources to take greater control of their lives and to advocate for themselves.

The participants also recognized the need to build greater knowledge and understanding of the cultures and life situations of other women of color including African Americans, Native Americans and Asians and Pacific Islanders in order to develop greater solidarity in the fight against HIV/AIDS.

Participants also stressed the importance of developing mechanisms to hold other women of color who are representing their communities and the needs of women of color accountable for their actions.

vi. Promote and Support Comprehensive, Holistic and Seamless Services

The participants identified fragmentation of services as a major barrier to access for Hispanic/Latina women and recommended the design and delivery of holistic and seamless services to address the HIV prevention and care needs of Hispanic/Latina women regardless of their immigrant or citizenship status.

They noted that prevention and care programs must integrate into the design and delivery of these services knowledge that many documented and undocumented immigrant women may fear disclosure of HIV status and its impact on their current or future status in the United States.

They noted that these services must be culturally competent and address differences in languages spoken, age, Hispanic sub-groups, national origin and levels of acculturation of the women to be served.

vii. Address the Needs of Special Populations

a. Immigrant Women

Participants identified the special needs of recent immigrant women. They noted that prevention and care programs must integrate into the design and delivery of these services knowledge that many documented and undocumented immigrant women may fear disclosure of HIV status and its impact on their current or future status in the United States.

Participants recommended that services for immigrant women provide linkages to comprehensive services, including primary healthcare, prenatal care, nutrition and family services. They stressed the importance of providing voluntary HIV counseling and testing as well as STD and tuberculosis screening in locations where the women are found. They also underscored the need for clinicians and care/service providers to be culturally competent and to understand the specific socio-cultural issues affecting health beliefs and behaviors of recently arrived immigrant women. Services targeted to this population must also include bilingual staff or make professional translation/interpretation services available for these women. Moreover participants emphasized the need to provide prevention and care/service information and materials, including informed consent forms, in the primary language and at the literacy and educational level of the women receiving the care/services.

Participants stressed the need to make anonymous HIV testing more available and accessible to immigrant women who may avoid getting tested because they are fearful of jeopardizing their residential or citizenships status if they test positive for HIV infection. Participants also noted that the current debate on HIV names reporting, engendered by CDC's recommendations regarding a national HIV-surveillance system, must address the HIV-testing issues specifically related to immigrants.

b. Incarcerated Women

Participants discussed the high rates of HIV infection and AIDS among Hispanic/Latina women who are incarcerated and emphasized the need to develop and expand HIV prevention and care services for this population within correctional facilities and transitional services when women are released back to the community.

Participants also identified the practice of allowing conjugal visits in some correctional facilities and the need to integrate HIV prevention education

for women who participate in these visits. Participants also suggested a pilot study to determine the level of risk for HIV infection among women who are involved in conjugal visits.

viii. Funding Needs and Strategies

Participants noted that federal, state and local funding is not easily accessible for programs developed by and for Hispanic/Latina women and Latino community-based organizations. They noted that funding sources generally want to fund replication of models that work with one population/community and apply the same approaches to other populations/communities based on the belief that “one size fits all.” They noted that, as stated above, culturally competent and tailored interventions and services are needed for Hispanic/Latina women. They recommended that funding sources engage Hispanic/Latina women in need assessment and priority setting and other processes to inform their decision-making regarding the development of their grant guidelines and requests for proposal. They also recommended that funding sources tailor requests for proposal to address the needs of Hispanic/Latina women and Latino communities in general.

Participants noted that funding sources such as the CDC and HRSA must develop greater understanding and appreciation for the specific needs of diverse populations. Very often when funding is targeted to minority communities or people of color the funding sources are really focusing on African Americans and are excluding other ethnic and racial minority populations/communities that also need services.

Participants recommended that funding sources support training and technical assistance for Hispanic/Latina women and organizations in order to strengthen their capacity to successfully compete for and secure HIV prevention and care services funding to develop and implement effective and tailored programs for Hispanic/Latina women.

Participants also recommended that funding sources at all levels require that providers demonstrate the ability to provide culturally competent services as a condition of funding and a standard for quality assurance.

Participants also recommended that funding sources assure that grantees recruit and employ culturally competent bilingual/bicultural management, supervisory and direct service staff to serve Latina/Hispanic and that the staffing plan and actual staffing pattern be a key component of the proposal review and approval process.

Participants recommended that funding sources at all levels direct more funding for program evaluation including formative, process and outcome evaluation.

Participants recommended that more funding be made available for community-based research developed and conducted by and for Hispanic/Latina women. They also identified the need for greater research funding to develop effective integration of HIV and STD prevention and treatment intervention strategies tailored for Hispanic/Latina women and for adolescents and young women.

Participants recommended that CDC and the National Institutes of Health (NIH) target more funding towards the development of women-controlled barrier methods including microbicides.

Participants recommended that outreach, prevention education and clinical services be brought to the places where the target populations are by funding mobile clinical care units and outreach and HIV testing vans.

Participants recommended that priority be given to expanding HIV prevention and care services in the border areas by targeting special initiatives and funding for such services.

Participants recommended that funders consider targeting resources to programs and interventions that focus on HIV prevention and care services for adolescent females including school-based services and programs that integrate the arts and culture into their strategies.

Participants recommended that both public and private funding for HIV prevention and care services for women-focused services be targeted to the Commonwealth of Puerto Rico, which has a significant burden of HIV and AIDS. They noted that due to Puerto Rico's unique political status in relationship to the U. S. (it is not a state nor independent nation) it often does not receive the level of funding needed to address its needs. They noted that corporate and foundation funders should place higher priority on funding community-based organization in Puerto Rico that are developing and providing women focused services.

Participants noted that the ban on the use of federal funding for needle exchange programs hampers efforts to effectively reach and deliver prevention and care services to active injection drug users. They urged that foundation and corporate funders give priority to supporting harm reduction strategies and interventions including needle exchange programs, particularly programs targeted to women.

Participants recommended that public and private funders give priority to funding programs that address the reduction of heterosexual transmission by targeting interventions to both men and women. They stressed the importance of strategies and interventions designed to engage and work with men and women together.

Participants stressed the importance of funding interventions targeted to women that are holistic, comprehensive and provide services within a “one-stop shopping” framework.

Participants recommended that funding sources at all levels give priority for funding to HIV prevention and care programs that are designed, developed and run by Hispanic/Latina women for Hispanic/Latina women.

Participants recommended that private funders target more resources to leadership development programs and advocacy skills training for Latinas and other women of color. They noted that women of color need the skills and support to participate more actively in HIV/AIDS policy and decision making processes on a federal, state and local level that affect their lives.

Participants recommended that federal, state and local funding agencies review their policies regarding administrative costs and develop more realistic allocations to cover administrative costs for grantees and sub-grantees. They noted that the current administrative cost ceilings disadvantage smaller organizations.

Participants recommended that the Centers for Disease Control and Prevention and the Health Resources Services Administration develop mechanisms to engage in joint planning and joint funding of initiatives and interventions that provide a seamless continuum of HIV prevention and care services for women. They stressed the importance of developing inter-agency partnerships at the federal level to assure the development and facilitate the delivery of such services at the state and local level. Participants also stressed the importance of including other agencies such as the Substance Abuse and Mental Health Services Administration in joint planning and funding initiatives.

Participants recommended that federal, state and local agencies responsible for HIV prevention and care services develop and implement training programs for their own program and grants management staff on cultural competence and delivery of services to culturally diverse populations in order to increase their knowledge and responsiveness to the needs of Latinos and other communities of color.

C. Asian and Pacific Islander Breakout Groups

i. Include Women in Policy Development and Decision-Making Processes

Participants noted that Asian and Pacific Islander women are excluded from participation in HIV-related planning and policy making bodies on the state and local level in part due to the use of surveillance data to identify affected populations. In areas where there is a high concentration of Asian and Pacific Islanders, women representing these communities should be included in HIV task forces, consortia, Title I Planning Councils and Prevention Community Planning Groups.

ii. Improve Data Collection, Surveillance and HIV/AIDS Reporting Systems

The participants identified the problems related to use of data for program planning and resource allocation particularly when there is no standard requirement to collect HIV/AIDS data by race/ethnicity and the national origin of Asian and Pacific Islander sub-populations. They recommended that federal, state and Local agencies develop standardized data collection systems that include disaggregated data on Asian and Pacific Islanders by gender and mode of transmission. Such data would enable more effective and targeted program development and resource allocation to different Asian and Pacific Islander sub-populations based on the trends in HIV and AIDS specific to each sub-group.

Participants also noted that due to the low numbers of officially reported cases among Asians and Pacific Islanders, sufficient funding is not targeted to these populations to support needed prevention and care programs. They recommended that federal, state and local funding agencies make special efforts to assess the impact of HIV/AIDS on Asians and Pacific Islanders particularly in areas where these populations are heavily concentrated through the use of special sero-surveys and data from surrogate markers for HIV risk such as drug use, other sexually transmitted diseases and tuberculosis.

Participants also stressed the importance of developing targeted initiatives to provide HIV prevention and care services and to support research targeted to the diverse Asian and Pacific Islander populations. They noted that services for these sub-populations are more costly because of the need to employ staff that understand the diverse cultural groups and can speak fluently the language of each targeted group. Funding sources very often do not take these factors into account when making resource allocation decisions. Asian and Pacific Islander communities are placed at a disadvantage when most funding decisions are made solely on the basis of AIDS and HIV surveillance data.

iii. Support Tailored, Culturally Competent HIV Prevention and Care Programs

Participants discussed the elements of culturally competent HIV prevention and care services for Asian and Pacific Islander women. They highlighted the need to develop comprehensive and integrated HIV and care service models that include primary and reproductive health care and address the psychosocial and economic issues that negatively impact women's health and well being.

Among the services that should be included are culturally competent outreach; prevention and risk-reduction education; women-focused treatment education and advocacy services; mental health, emotional support and substance abuse services; domestic violence services; housing services; legal and immigration services; voluntary HIV counseling and testing services; childcare; and transportation services.

Participants emphasized the importance of integrating an understanding of socio-cultural factors discussed below into the design of HIV prevention and care/service programs targeted to Asian and Pacific Islander women. They underscored the need to deliver tailored services responsive to the needs of the specific sub-populations based on providers' understanding of the variations regarding the impact of cultural values and norms, immigrant status and socioeconomic status on Asian and Pacific Islander women.

Participants also noted that prevention and care services must be delivered in a manner that is responsive to the needs of lesbian and transgendered Asian and Pacific Islander women. They noted that there are few culturally competent health care delivery services targeted to Asian and Pacific Islander, and there is a paucity of culturally competent staff in lesbian and transgendered health clinics and services.

They also stressed the importance of developing and implementing programs to meet the HIV prevention and care needs of adolescents and young women and indicated that there is a paucity of such services available in their communities.

a. Address Socio-cultural and Economic Diversity

Participants identified the diversity in national origin, languages spoken, cultural beliefs and socio-economic status of different sub-populations of API women. Asians in the U.S. represent 29 ethnic and national groups, and Pacific Islanders represent 19 ethnic and national groups, who speak more than 100 different languages. The participants recommended that HIV prevention and care programs for API women take into account the specific

Asians in the U.S. represent 29 ethnic and national groups, and Pacific Islanders represent 19 ethnic and national groups, who speak more than 100 different languages.

national origin, language and culture of the women to be served in the design and delivery of these services. Participants also noted that tailoring programs is essential because of the variations in HIV/AIDS trends among different sub populations of Asians and Pacific Islanders.

Participants noted that a large proportion of the Asian population in the U.S. is comprised of newly arrived immigrants and foreign-born individuals who speak their native language. Thirty-eight percent (38%) of Asians entered the country between 1980-1990. Cambodians, Laotians and Hmong had the highest proportion of persons who entered the U.S. during this period. While 87% of the Pacific Islander population were born in the U.S., 66% of Asians were foreign-born. Among the Asian groups, Vietnamese, Laotians, and Cambodians had the highest proportion of foreign born, while Japanese had the lowest proportion.

They also noted that there are significant differences in socioeconomic status among API sub-groups. The Hmong (63.6%) had one of the highest poverty rates, followed by Cambodians (42.6%) and Laotians (34.7%). Filipinos had the lowest poverty rate (6.4%). Among Pacific Islanders, Samoans had the highest poverty rate (25.8%) followed by Tongans (23.1%), while Hawaiians had the lowest poverty rate (14.3%).

Participants noted that differences in health beliefs, behaviors and attitudes regarding healthcare utilization may influence API women's level of trust of the health care system and their follow through with HIV related care. The following are among the cultural issues that impact health beliefs and behaviors that must be addressed in order to provide effective services.

1. Patriarchy

Many Asian cultures are patriarchal, where men hold the power and control in relationships, women are not valued while men are prized, and women are seen as a commodity or a burden to their families. These cultural values and norms may contribute to low self-esteem for API women and increase vulnerability to HIV infection.

2. Taboos

Participants noted that many Asians have cultural taboos against speaking openly about sexual relationships and sexuality, drugs and drug use, and disease and death. These cultural taboos must be understood and respected by service providers in order to effectively reach these populations.

3. Saving Face

Participants also noted that saving face and protecting the family's honor by keeping problems within the family network are strong values in many Asian cultures. The needs of the individual are therefore secondary to the needs of the family and community. Individuals are expected to

suffer in silence and not ask for help outside of the family network. Moreover issues and problems are not discussed in public or outside of the family network, and individuals are expected to behave in a manner that will make the family look good and uphold the family's honor.

4. *Myth*

Participants noted that many Asian individuals, particularly those who lack basic education, have a tendency to believe in myths. This influences perceptions regarding risk for HIV infection and may fuel stigma and denial.

5. *Respect for Elders*

Participants noted the strong emphasis on respect for the wisdom and authority of elders in Asian cultures. Because of the differences in levels of acculturation among different populations and age groups of Asians, intergenerational conflicts may occur that affect interpersonal communication and family relationships. API women who are more acculturated to the U.S. culture may, for example, experience greater intergenerational conflicts with their elders than less acculturated, newly arrived women who are more closely bound to their traditional cultural values.

b. *Address Language Diversity in Program Planning and Service Delivery*

HIV prevention and care/services materials and information must be provided in the primary languages of API women. Due to the diversity of languages spoken by different API sub-groups, programs will need additional funding to provide information and services. Funding should be used to hire staff who speak the languages of the targeted populations and to offer translation and interpreter services when such staff are not available. Additional funding will also be needed to develop written and audio-visual educational and informational materials in the languages spoken by the targeted populations. In addition, program planning must address referral and linkage services to culturally appropriate ancillary and supportive services that are delivered in the languages spoken by the target populations.

c. *Provide Services in the Venues Where People Are*

Participants noted that many API are working long hours and several jobs to support and care for their families. Because work and family responsibilities will take precedence over self-care, strategies to reach API women must include delivery of services in the venues and through the organizations where they are most likely to be found. These include but are not limited to community organizations and businesses, such as religious organizations, community centers, nurse and physician associations, clothing stores and restaurants.

They also noted that many women are involved in the sex industry as a means of survival. Strategies to reach sex industry workers should include outreach through members of the community and businesses with routine access to sex workers, including taxi drivers and bartenders and in venues such as sex clubs, massage parlors and adult book and video stores.

Such outreach should be followed up with interventions that place HIV in the context of other health issues that API women face such as other sexually transmitted diseases, tuberculosis and cervical cancer.

d. Promote Peer-Led Interventions

Participants stressed the importance of utilizing peer-led interventions for outreach and to engage API women. Peers can provide an effective bridge to cross cultural differences and develop trust. Moreover, peers can promote exploration of cultural values and norms that impact women's perceptions of risk for HIV and support linkage to appropriate HIV prevention and care services.

Participants stressed the importance of including API women in the processes related to planning, designing and implementing prevention and care/service programs.

e. Promote Community Level Interventions

Participants recommended the development and funding of community-level interventions, school-based outreach and public information campaigns. Such interventions can provide an effective mechanism to reach recent immigrant women and to disseminate information regarding HIV prevention and available care/services. The participants stressed the importance of using mass and cultural media including native language newspapers, radio, television, theater and performers to disseminate HIV prevention health promotion and care information and messages.

f. Address Domestic Violence and Sexual Abuse/Assault

Participants discussed the role of domestic violence and sexual abuse/assault in increasing API women's vulnerability to HIV infection. They recommended that screening for domestic violence and sexual abuse/assault be integrated into the services offered API women and that health care providers be trained to identify signs of these problems. The participants emphasized that API women may not easily disclose domestic violence or sexual abuse because of cultural norms related to the subordinate role of women in heterosexual relationships and taboos regarding discussion of sexual and family matters outside of the family.

g. Understand and Integrate Traditional Medicine and Healing

Participants discussed the importance of traditional healing and medicine for APIs and indicated that culturally competent services must integrate an understanding and respect for these non-Western beliefs and practices. The participants strongly recommended that health care providers, including doctors, learn more about the alternative and traditional therapies used by API women and how these therapies and practices impact HIV care for women living with HIV.

h. Integrate Case-Management and Client Advocacy Services

Participants noted that newly arrived immigrants and foreign-born women with limited English proficiency face significant hurdles in navigating complex health and human services systems. Due to changes in benefits for legal immigrants as a result of Welfare and Immigration reform measures, many API women need assistance in applying for and obtaining benefits and services. The participants recommended that funding be provided for client advocacy, case management and treatment education services as part of a continuum of comprehensive HIV services for this population. These services are needed to help women navigate the complex service delivery systems, to learn about their consumer rights, and to improve access and link them to needed HIV care and supportive services.

i. Integrate Legal and Immigration Services

Participants noted the large number of documented and undocumented immigrants and foreign-born among API populations in the United States. They stressed the importance of integrating immigration and legal services into HIV prevention and care in order to effectively address problems encountered by women related to their immigrant status. They also pointed out that these services might serve as a point of entry to engage and link women to HIV prevention and care services.

j. Address Food and Nutritional Needs of Diverse Sub-populations

Participants noted that most food and nutritional services for HIV positive persons are based on the dietary preferences of the dominant Anglo culture. They recommended that food and nutritional service providers integrate the culturally based dietary preferences and patterns of different API sub-groups in the delivery of these services to said groups. This requires tailoring the menus for home-delivered meals and the stock for food banks to address the dietary and nutritional preferences of these sub-groups.

iv. Promote Behavioral and Sociocultural Research

Participants stressed the need for more research on the impact of cultural norms on the attitudes and beliefs of women of different API sub-groups regarding health and self-efficacy. Although the impact of these norms may be stronger among recent immigrants who have not been acculturated, they also impact behavior among API women who have been in the U.S. longer as well as the American-born.

The participants also highlighted the need to promote research related to the specific HIV risks, prevention and care needs of transgendered (male-to-female) persons. They noted that there are significant numbers of male-to-female transgendered persons who are at risk of HIV infection due to involvement in sex work. They also noted that HIV prevention and care services are not responsive to the specific needs of this population and greater knowledge is needed to design effective prevention interventions and care services.

The participants emphasized that programs aimed at Native American women must address differences in culturally prescribed gender roles depending on whether a tribe is patrilineal or matrilineal.

v. Address Stigma and Assure Confidentiality

Participants discussed the significant role stigma plays in fueling the spread of HIV within API communities. They noted that many women fear they will be ostracized within their own communities if their HIV status is disclosed and that they will bring shame to their families. In order to avoid disclosure many at-risk women do not seek HIV counseling and testing services. Those that are HIV positive may delay entry into care until they have progressed significantly in their illness in order to avoid disclosure and the attendant negative consequences.

Moreover, many immigrant women fear that disclosure of their HIV status will jeopardize their residency in the U.S.

Participants agreed that strategies to address the impact of stigma on the utilization of HIV prevention and care services by API women are sorely needed and should be prioritized for funding. Moreover, they stressed the importance of developing adequate methods in service delivery systems to assure the confidentiality of the women being served.

vi. Include API Women Living with HIV/AIDS in Program Planning

Participants stressed the importance of including API women living with HIV/AIDS in HIV service organizations' boards and advisory boards to ensure their meaningful input into program design and implementation.

D. Native American/Alaskan Native Breakout Groups

i. **Include Women in Policy Development and Decision-making Processes**

The participants identified the lack of adequate representation of Native American women in HIV planning, decision-making bodies and policy-making bodies. They noted that this is due in part due to the use of surveillance data to identify affected populations. Since Native Americans represent relatively low numbers in national and state HIV and AIDS statistics, they are often not viewed as a segment of the affected communities that should be include in these bodies. The participants recommended that federal, state and local funding agencies make special efforts to assure the inclusion and adequate representation of Native American women in decision-making and policy development processes related to HIV/AIDS such as prevention community planning groups, community advisory boards, HIV planning councils and consortia. This should be done in areas where there are high concentrations of Native Americans as well as places where Native Americans are dispersed within the general population.

Participants also identified the need for greater representation of Native Americans in key program and policy staff positions in federal agencies with responsibility for implementing HIV/AIDS related prevention, care and research programs such as the Health Resources and Services Administration (HRSA), the Centers for Disease Control and Prevention (CDC), the substance Abuse and Mental Health Services Administration (SAMSHA) and the National Institutes of Health (NIH). The participants strongly recommended that federal agencies step up their efforts to assure Native American representation in order to facilitate the inclusion of Native American issues and needs in internal planning and decision-making processes.

ii. **Improve Data Collection, Surveillance and AIDS/ HIV Reporting Systems**

The participants discussed the problems associated with planning and funding services targeted to Native American populations and particularly women when HIV data is used to justify the need for services. They noted that AIDS and HIV case reporting does not provide good indicators of the trends in the epidemic among Native Americans because two-thirds of the Native American population is concentrated in 10 states (Oklahoma, California, Arizona, New Mexico, Alaska, Washington, North Carolina, Texas, New York and Michigan) and three of the 10 do not report HIV infection cases (Alaska, California and Washington). New York just began implementation of confidential HIV case reporting in January 1999, and New Mexico began in January 1998.

The participants also noted that undercounting of Native Americans in HIV/AIDS reporting is affected by the misclassification of Native Americans as white, Asian or Hispanic by health workers and officials and the exclusion of Native Hawaiians from HIV/AIDS reports among Native Americans. In addition, most tribes do not report HIV/AIDS surveillance data to the Indian Health Service (IHS), to state health departments or to the CDC. The IHS does not routinely collect such information from the tribes. The problems associated with case reporting by the IHS to state health departments and CDC also leads to under-counting.

Federal, state and local policy makers, as well as officials of Tribal governments and the IHS, may not see HIV/AIDS as a top health and human service priority because of the low trends of HIV/AIDS morbidity and mortality among Native Americans reflected in official reports.

Participants recommended that efforts be made to address these reporting and data issues by the federal government in collaboration with tribal governments and the IHS to develop a surveillance system that accurately collects data on Native Americans.

Participants also recommended that CDC, HRSA and SAMHSA use other mechanisms, including focus groups to assess the HIV prevention and care service needs of different Native American sub-groups.

They recommended that data on Native American HIV infection and AIDS rates be calculated in relation to the population of Native Americans rather than the entire U.S. population. They also recommended that sero-surveys be conducted in states, municipalities and tribal nations where there is a high concentration of Native populations. Participants also stressed the need to provide technical assistance and training to health professionals about the problems related to misclassification of Native Americans in data collection and more effective ways to collect, interpret and use data related to HIV/AIDS for program planning and resource allocation purposes.

Participants underscored the need for both public and private funding agencies to give Native American issues priority and not continually overlook this population because of their low numbers in official surveillance data.

iii. Promote Social-cultural, Clinical and Behavioral Research

Participants discussed the lack of research on Native American populations focused on the impact of social, economic, cultural and spiritual factors on HIV prevention, risk reduction and clinical care. They noted that more targeted and tailored research is needed to examine how cultural norms and beliefs about health and wellness impact protective factors and self-efficacy.

They also noted that research is needed to further explore the relationships between such factors as the rates of drug and alcohol abuse, sexual abuse and domestic violence, other sexually transmitted diseases and vulnerability for HIV infection among Native American women. Participants noted that cultural values and norms as well as stigma contribute to denial and silence related to HIV/AIDS among Native Americans.

Participants also noted that there are significant differences between the factors impacting risk and protective behaviors among Native Americans living on reservations, off reservations in rural areas and in urban areas. These differences must be examined more closely to develop more effective prevention and care related strategies to address the different needs of these populations. In addition, tailored research efforts on HIV/AIDS prevention and care should examine such factors as the impact of traditional Native American values, spiritual beliefs, traditional healing practices and such factors as bi-directional migration between reservations, rural areas off reservation and urban areas.

The participants recommended that federal agencies such as NIH, HRSA, SAMHSA and CDC work with tribal governments and the IHS to develop joint strategies for research on the various psychosocial, behavioral and clinical issues related to HIV/AIDS among Native Americans.

iv. Support Tailored, Culturally Competent HIV Prevention and Care Programs

The participants discussed the impact of culture and socioeconomic factors on HIV prevention and care and stressed the importance of developing and implementing culturally competent and tailored interventions for diverse Native American populations. They recommended that culturally competent HIV prevention programs be designed and implemented to incorporate the key cultural values, norms and practices of the targeted Native American population. They stressed the importance of integrating tribal traditions to communicate messages and carry out interventions. These interventions should address how cultural values; beliefs and practices influence perceptions about health, health promotion, wellness and health behaviors.

a. Address Culturally Prescribed Gender Roles

The participants emphasized that programs aimed at Native American women must address differences in culturally prescribed gender roles depending on whether a tribe is patrilineal or matrilineal. They stressed that interventions aimed at women must incorporate strategies that respect cultural values and integrate approaches that are in sync with the tribal culture and role of women in that particular Native Nation. They also stressed the importance of involving Native women in every step of the process of program planning, design, implementation and evaluation in

order to assure the cultural appropriateness of the interventions. The participants also discussed the importance of involving women in action groups to cultivate leadership and promote empowerment of Native American women in response to the health challenges in their communities.

Participants recommended the use of theater as a mechanism to address HIV prevention issues with Native American women and urged funding sources to consider supporting such interventions.

b. Promote Peer-Led HIV Prevention and Care Interventions

The participants stressed the importance of cultural compatibility and matching between the service providers and Native group being targeted for services and interventions. They recommended the use of trained peer educators and health workers to deliver the services.

They stressed that the persons carrying out the interventions and delivering the HIV prevention and care services must be Native people who understand the cultural nuances and patterns of the Native group they are trying to reach. These educators and health care workers must be familiar and friendly with the community and have knowledge about its traditions and key gatekeepers, including clan mothers, tribal leadership and medicine people of that community. Educators and health care workers must recognize the importance of meeting with the tribal councils and leaders to discuss their intentions and regarding the delivery of HIV prevention and care services. Tribal leaders must also be integrated into the planning and design of interventions.

They also stressed the importance of making funding available to effectively train and support peer educators and health workers as well as program supervisors and managers.

c. Support the Development of Culturally Appropriate Information and Materials

The participants stressed the importance of developing materials, information and communication media that respond to the communication methods and patterns of diverse Native American sub-groups.

d. Address the Needs of Native Americans Living on Reservations

The participants noted the poverty and concomitant psychosocial problems faced by many Native Americans living on reservations. They recommended prevention and care services targeted to persons on reservations that are community focused and based on the social and cultural systems within the reservation. The participants stressed the importance of using culturally based strategies as a mechanism to build trust and communicate more effectively with the persons to be reached.

The participants also noted the bi-directional migration of Native Americans between reservations, other rural areas and urban centers. They recommended that programs aimed at Native Americans assure continuity of HIV prevention, care and services for migrating individuals and families that have limited access to health care and other resources.

Participants identified concerns regarding the erosion of traditional values, norms and practices of Native Americans by the forces of assimilation and the onslaught of acculturation. They recommended that strategies that reconnect young Native Americans with their traditional roots be incorporated into HIV prevention and care services. In providing HIV prevention services, for example, the participants recommended educating youth on Native American beliefs regarding sexuality, the roles of men and women, traditional rites of passage, ceremonies and spirituality.

e. Address the Needs of Native Americans Living Off Reservations in Rural Areas

Participants noted that a significant proportion of the Native American population also live off reservations in rural areas. They discussed the challenges faced by persons in rural communities due to isolation, the long distances to access services and the lack of availability of local health and social support services, particularly HIV-related ones. The participants also noted that rural community residents are often negatively impacted by intertribal relations, lack of recognition of certain tribes by the federal government, and state or federal policies or regulations regarding the provision of health care services within tribes.

f. Address the Needs of Native American Living in Urban Areas

The participants noted that the urban Native American population is disproportionately affected by many social and behavioral factors that contribute to the disparities in health outcomes and increased vulnerability for HIV infection. This population is relatively young and has high rates of poverty, sexually transmitted diseases, and drug and alcohol abuse. The policy of forced relocation of Native Americans by the federal government to urban areas, coupled with the racism and discrimination they encountered, have led to a legacy of high rates of poverty, unemployment, welfare dependency, obesity, diabetes, alcoholism, substance abuse and family violence.

Participants stressed the importance of urban Indian health centers in providing services to Native Americans living in urban areas and recommended that the federal government target additional resources to fortify the services of these health centers and encourage them to expand HIV-related prevention and care services.

Participants also recommended that CDC make greater efforts to ensure that states and jurisdictions receiving federal HIV prevention resources step up their efforts to increase the representation of Native Americans on prevention community planning groups through targeted recruitment, training and support for meaningful participation and retention strategies.

g. Address the Special Needs of Adolescents and Youth

The participants recommended that programs targeted to Native American adolescents and youth also address the impact on HIV prevention and care of mental health issues, including family violence; sexual assault and abuse; high rates of teen pregnancy; alcohol and substance abuse (including heroin, crack, and inhalants); and gang membership, initiation rites and tattooing. They recommended that HIV prevention programs integrate education about traditional Native American values and beliefs regarding sexuality, gender roles, rites of passage and ceremonies into their education and intervention approaches for this population.

v. Integrate HIV Prevention and Care with Primary Health Care and Other Services

The participants noted that services for Native Americans should be community-based strategies designed to respond to the many health and socio-economic issues impacting the lives of the people. They noted that just focusing on HIV/AIDS would not be effective when the persons being targeted are confronting a whole host of health and mental health problems. The participants recommended a service model that integrates HIV prevention and care services with primary health care, substance abuse, mental health and supportive services. According to the participants, Native Americans are heavily impacted by substance abuse, mental illness and their sequelae, including fetal alcohol syndrome; diabetes; high blood pressure; heart disease; poor nutrition; cervical, breast and lung cancer; infectious diseases such as hepatitis, other sexually transmitted diseases (STDs) and tuberculosis (TB); unintended pregnancy; infant mortality; domestic violence; and spousal, child and sexual abuse.

Participants discussed the key role of IHS facilities in providing health care services to Native Americans and recommended that federal officials support and fund greater HIV prevention and care services, voluntary counseling and testing within IHS funded substance abuse treatment and prevention programs and health care clinics.

Participants raised concerns regarding policies underway to institute name-based HIV case reporting. They stressed the importance of providing voluntary

HIV counseling and testing to Native American women in a safe and non-coercive environment. They emphasized the need to develop strategies to ensure confidentiality and minimize HIV-related stigma and the attendant negative consequences related to disclosure of HIV status. Programs that effectively assure confidentiality and address disclosure issues are more likely to encourage more women to seek HIV testing and learn their HIV status.

vi. Promote Interagency Coordination

Native Americans face specific challenges in accessing prevention and care services due to the characteristics of the service delivery systems available to them through the IHS, tribal health services, urban Indian health centers, and state and local services. The participants recommended that federal agencies such as CDC, HRSA, SAMHSA, NIH and IHS develop mechanisms for interagency cooperation, collaboration and planning to create more effective service delivery to Native American populations.

vii. Promote Mechanisms to Encourage Networks for National and Local Action Among Native American Women

The participants articulated the importance of providing forums and mechanisms for Native American women from different parts of the country to come together to share information and develop networks for local and national action on HIV and related issues affecting their communities' health and well being. They recommended that private funders provide resources to support such grassroots organizing and networking activities as part of their initiative to address HIV and other health concerns among Native American women. Such activities would include support for newsletters and other communication vehicles as well periodic information exchange and planning meetings.

Endnotes

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- ²⁰ Kaiser Commission on Medicaid and the Uninsured, *Key Facts: Health Insurance Coverage and Access to Care Among Latinos*, June 2000.
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Appendices

Empowerment: A Strategy for HIV/AIDS Prevention and Access to Care

Among Women of Color Conference—Houston, Texas—June 23-26, 1997

Conference Objectives

- To provide opportunities for women of color living with HIV and care/service providers to share successful and innovative program strategies that have increased HIV prevention outcomes and access to HIV care and supportive services for women in their communities.
- To provide opportunities for CDC to share with participants the results of on-going prevention programming and evaluation studies focused on women and to provide a forum for the discussion of their implications for population-tailored program design, implementation and resource allocation.
- To provide opportunities for HRSA to share with participants the results of on-going HIV care and support service delivery and evaluation studies focused on women and to provide a forum for the discussion of their implications for population-tailored service delivery design, implementation and resource allocation.
- To provide a forum for women of color living with HIV and service providers to explore and define the elements of culturally competent, holistic, empowerment-based prevention/HIV care approaches geared to diverse populations/subpopulations of women of color.
- To provide opportunities for women of color living with HIV and care/service providers to develop a framework to integrate these features in prevention and care models tailored for specific sub-populations of women of color.
- To document recommendations for consideration by policy-makers, funders and community-based organization managers on the implications of such models for program design, implementation and resource allocation.
- To provide a forum for women of color living with HIV/AIDS and care/service providers to discuss the potential impact of managed care service delivery systems on access to quality HIV care and supportive services for poor, underserved populations of women.
- To provide opportunities for HRSA staff and conference participants to identify critical factors to be considered by managed care providers in developing services to meet the HIV-care needs of poor, underserved women living with HIV and their family networks.

Format

The format for this three day working conference was designed to promote the exchange of the socio-cultural perspectives and HIV prevention/care experiences/expertise of the diverse participants, to provide updates in the progress of HIV prevention interventions and HIV care service delivery among women of color and to facilitate working sessions which will expand knowledge and understanding of the implications of ethno/racial and demographic diversity for HIV prevention and care service models for women of color. Sub-population breakout sessions explored the applicability of various models of empowerment for HIV prevention/care among these diverse groups. Roundtable sessions focused on developing consensus on the key elements of HIV prevention/care service models tailored for particular subpopulations of women.

The conference consisted of three and one half days of plenary sessions, workshops and facilitated roundtables as well as social activities, where participants shared their expertise and experiences in HIV/AIDS prevention/education programs and HIV care service delivery, as well as expanded their professional network.

Conference Planning Committee

The conference planning committee consisted of approximately 15 women of color representing a cross-sectional balance in terms of HIV status, ethnic/racial (African American, Hispanic/Latina, Asian Pacific Islander and Native American) group, expertise and geographic region. Members were drawn from a pool of women identified as experienced and knowledgeable in delivering tailored HIV prevention and care services for women of color, as well as, women living with HIV/AIDS. The planning committee assisted in the development of the specific agenda content; identify speakers/presenters for the various plenary sessions, panels and workshops; identified skilled facilitators for the roundtable sessions; and drafted the evaluation instruments.

The goal was to draw from a pool of presenters, speakers and facilitators representing a cross-section of professional individuals who serve many segments of the diverse communities impacted by HIV/AIDS; women living with HIV/AIDS who have been advocates and activists; and individuals with recognized skills and abilities in program design, HIV behavioral research, HIV care service provision and group facilitation skills.

Miguelina León, NMAC's Director of Government Relations & Policy and the Women's Program, convened the committee. Also included in the planning process were CDC and HRSA staff assigned to this project. In addition, cooperating CBOs in Houston were approached to form a local host committee, which assisted in planning special social events. Communication with the planning committee was facilitated through conference calls and on-going correspondence.

National Minority AIDS Council Empowerment Conference

June 23-26, 1997

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EMPOWERMENT I

sponsored by the National Minority AIDS Council
Centers for Disease Control & Prevention
Health Resources Services Administration
Westin Oaks Hotel, Houston, Texas
June 23-26, 1997

Agenda

Sunday, June 22, 1997

3 pm - 8:00 pm **Registration - Grand Foyer**

Monday, June 23, 1997

8:00 am - 9:00 am **Registration & Continental Breakfast - Grand Foyer**

9:00 am - 9:50 am **Opening Plenary - Consort I**

Welcome and Conference Overview

Miguelina Leon

Director of Government Relations and Policy

National Minority AIDS Council

Washington, DC

Sheila Cort Isoke,

Project Officer National Center for HIV, STD & TB Prevention

Centers for Disease Control & Prevention

Atlanta, GA

LaVerne Green-Frazier,

Project Officer

Division of Programs for Special Populations,

Bureau of Primary Health Care,

Health Resources Services Administration

Bethesda, MD

Navajo Prayer, National Anthem in Navajo

Kathyrnn Arviso,

Navajo Tribe, Crown Point, NM

Libation

Sophia Jones Redmond

Director of Prevention and Education

Cook County Hospital Women/Children's HIV Program

Chicago, IL

9:50 am - 10:40 am

General Session - Consort I

Epidemiological Trends of HIV/AIDS Among Women of Color: Current Issues/Future Directions

This presentation will provide an overview of the HIV/AIDS morbidity and mortality trends among women in the United States by race/ethnicity, age, geographical region and mode of exposure. The presenter will discuss the current trends in HIV prevention among women including reductions in perinatal transmission, the role of STD prevention and treatment in reduction of HIV transmission, lessons learned from prevention interventions and behavioral research and the implications for future targeting of prevention activities and resources.

Allyn Nakashima, MD

Medical Epidemiologist, Surveillance Branch

National Center for STD, HIV & TB Prevention,

Centers for Disease Control & Prevention

Atlanta, GA

Risk Behaviors for HIV/AIDS Among Women of Color in the United States.

This presentation will describe the epidemiological trends in HIV/AIDS among women, using data from national HIV/AIDS surveillance, the Supplement to HIV/AIDS Surveillance (SHAS) study and a study of high risk youth from urban areas (Miami, New York and San Francisco). Trends in IDU related HIV/AIDS transmission and heterosexual transmission will be discussed and the connection between substance use and heterosexual transmission will be examined. Reducing substance abuse (both injecting and non-injecting drug use) will be highlighted as a key strategy for prevention of HIV among women.

Allyn Nakashima, MD

Medical Epidemiologist, Surveillance Branch

National Center for STD, HIV & TB Prevention,

Centers for Disease Control & Prevention

Atlanta, GA

Questions & Answers

10:40 am - 10:55 am

Break

10:55 am - 11:20 am

Consort I

Reducing HIV Infection among Substance Abusing Women: The Role of Needle Exchange Programs in HIV Prevention

This presentation will focus on the special needs of female substance abusers who are at risk for HIV infection and provide an overview of intervention strategies that have been effective in reducing HIV infection among injecting and non-injecting drug users.

*Alma Candelas,
Director of Special Populations
New York State Department of Health, AIDS Institute,
New York, NY*

Questions and Answers

11:20 am - 11:45 am

Consort I

Meeting the HIV/AIDS Care Needs of Women: Implications of Managed Care on Access to Quality HIV Treatment and Care

This presentation will provide an overview of the care needs of women living with HIV/AIDS and discuss the implications of the breakthroughs in anti-HIV therapies for women. Trends in the shift to managed care, including Medicaid managed care will be described and the implications of these changes in health care service delivery for access to HIV/AIDS care and treatment for poor, underserved women will be explored.
(cancelled)

11:45 am - 12:30 pm

Consort I

In Our Own Voices: Women of Color Living with HIV/AIDS

Women living with HIV/AIDS of diverse ethnic/racial groups will provide their perspectives on the key HIV prevention issues facing their communities and the strategies that need to be undertaken to reduce HIV infection among women.

*Karen McManus,
Executive Director, Women of Color AIDS Coalition
Boston, MA*

*Kwan Bennett-Benbow,
Consultant, Women's Project
Asian & Pacific Islanders Coalition on HIV/AIDS, New York, NY*

*Cordelia Thomas,
Health Educator
Ahalaya Project-Tulsa Office, Tulsa, OK*

*Irma Villa Vasquez,
Speakers Bureau Coordinator
Albuquerque Area Indian Health Board, Inc.,
Albuquerque, New Mexico*

Questions and Answers

12:30 pm - 1:45 pm

Lunch on Your Own

1:45 pm - 3:15 pm

Concurrent Workshops

A) HIV Prevention Interventions for Women with Special Needs

Embassy Room

This session will address special considerations and HIV prevention strategies to reach sex workers, substance abusers and incarcerated women.

*Maria Alvarez,
Community Education Specialist
PROCEED, Inc., Elizabeth, NJ*

*Vivian Torres,
Program Director
St. Columba Neighborhood Club, Newark, NJ*

*Phyllis Green,
HIV Educator/Outreach Worker
Hispanic AIDS Committee, San Antonio, TX*

*Irene Suico Soriano
Program Coordinator,
Asian Pacific Health Care Venture Inc, Los Angeles, Ca*

*Cecelia (Cissy) Elm,
Outreach Education Coordinator
American Indian Community House, Syracuse, NY*

Questions and Answers

B) HIV Prevention Strategies and Interventions for Rural and Immigrant Populations

Consulate Room

This session will address the special needs and issues confronting women who are immigrants, and those who live in rural areas. Presenters will address the issues confronting Haitians, Asian & Pacific Islanders, Latinas, women living in rural areas in different regions of the country, border areas and Native Americans living on or near reservations. Barriers to HIV prevention and strategies to reach women in these communities will be discussed.

*Marie Carmel Louis-Pierre,
Program Director,
Haitian Centers Council, Brooklyn, NY*

*Karen Kimura,
Director of Women's Prevention Services
Asian Pacific AIDS Intervention Team, Los Angeles, CA*

*Gloria Casas,
Women's Health Center Manager
Su Clinica Familiar, Harlingen, TX*

*Gwen Bampffield-Wright,
Director of Prevention & Care Services
The ACCESS Network, Inc., Hampton, SC*

*Edith Miller,
Member
Midland's HIV Task Force for Women, Columbia, SC*

*Cordelia Thomas,
Health Educator
Ahalaya Project-Tulsa Office, Tulsa, OK*

*Elba Pacheco Rivera,
Executive Director
Casa Pensamiento, Aibonito, PR*

Questions and Answers

C) HIV Prevention Strategies to Address the Needs of Women of Diverse Sexual Orientations and Identities

Continental Room

This workshop will focus on prevention approaches and strategies which are designed to address the diversity of

women's sexual orientations and identities. Presenters will address the psycho-social, cultural, economic and behavioral factors which impact on HIV prevention for women based on their sexual orientation/identity.

They will also discuss the key elements that need to be incorporated in prevention interventions to reach the range of populations that they serve.

*Maria Isabel Báez,
Director of Prevention Services
Fundación SIDA de Puerto Rico, San Juan, PR*

*Leanne Guy,
Coordinator, HIV/STD Prevention Project
Inter-Tribal Council of Arizona, Inc., Phoenix, AZ*

*Michelle Lopez,
Community Organizer
Community Family Planning Council, New York, NY*

Questions and Answers

D) Interface: Domestic Violence, Sexual Abuse and HIV Prevention

Oak Room

This workshop will explore the psycho-social needs of women who have experienced domestic violence and/or sexual abuse and the challenges raised for HIV prevention efforts. The presenters will address the various factors which can place women at risk for domestic violence and sexual abuse and examine strategies to work with at risk women in order to reduce their risk of HIV infection.

*Apurva Uniyal,
Associate Manager
Asian Pacific Health Care Venture, Los Angeles, CA*

*Pandora Singleton,
Executive Director
Project Azuka, Inc, Savannah, GA*

*Yolanda Rodriguez-Escobar,
Clinical Social Worker
FFACTS Clinic, University Health System
San Antonio, TX*

Questions and Answers

3:15 pm - 3:30 pm

Break

3:30 pm - 6:00 pm

Breakout Sessions

Facilitated breakout sessions by subpopulation of women of color. Participants will hear a 30-minute panel presentation on the key HIV prevention issues and challenges for women of color for the particular subpopulations they are addressing in their breakout session. Examples of strategies that have worked will also be provided. Facilitators will then lead a discussion to generate from the participants their perspectives on the HIV prevention needs, the socio-cultural, economic, and psychological factors that impact on HIV prevention and the specific HIV strategies which they feel will work to reduce the risk of HIV infection and promote behavioral changes among the subpopulations they are addressing.

A) Women of African Descent Continental Room

B) Latinas Consulate Room

C) Asian & Pacific Islanders Oak Room

D) Native Americans Embassy Room

6:00 pm - 6:30 pm

Break

6:30-8:00 pm

Reception - The Roof

Tuesday, June 24, 1997

8:00 am - 9:00 am

Registration and Continental Breakfast

Grand Foyer

9:00 am - 12:30 pm

Plenary Session - Consort I

9:00 am - 9:10 am

Welcome and Announcements

Miguelina Leon,

Director of Government Relations

National Minority AIDS Council, Washington, DC

9:10 am -10:35 am

Developing HIV Prevention Strategies: Responding to the Context and Realities of Women's Lives

This panel will examine the socio-cultural, psychological, economic and geographical factors which must be considered in designing HIV prevention strategies for women of color of diverse ethnic, racial, and cultural backgrounds, living in different regions of the country and territories. Speakers will address the specific issues related to the respective subgroups they serve and present

examples of culturally competent, comprehensive and holistic models that have worked in their communities.

*Irene Suico Soriano,
Program Coordinator
Asian Pacific Health Care Venture, Los Angeles, CA*

*Leanne Guy,
Coordinator HIV/STD Prevention Project
Inter Tribal Council of Arizona, Phoenix, AZ*

*Dawn McKinley,
Health Educator
Urban League of Greater Hartford, Hartford, CT*

*Maria Isabel Báez,
Director of Prevention Services
Fundacion SIDA de Puerto Rico, Rio Piedras, PR*

*Marie Carmel Pierre-Louis,
Program Director
Haitian Centers Council, Brooklyn, NY*

*Charlene Ortiz,
Human Service Worker
Denver Public Health Department, Denver CO*

Questions & Answers

10:35 am -10:50 am

Break

10:50-12:05 am

Empowerment: A Strategy for Survival: Voices of Women Living with HIV/AIDS - Consort I

Participants will share their personal process of empowerment within the context of the challenges they experience on a day to day basis as women living with HIV/AIDS. They will also describe the activities they have or are currently participating in which address HIV/AIDS in their communities and how they became involved in advocacy and community service.

*Virginia Peña,
Co-Facilitator Recovery Support Group
Conn. Pediatric AIDS Program, UCT Health Center, West Hartford CT*

*Elizabeth Banks,
Member,
East Boston Health Center's AIDS Task Force, Dorchester, MA*

*Ellen J. Jones,
Member, Native American Leadership Commission on
HIV/AIDS, New York, NY*

*Kwan Bennett-Benbow)
Consultant, Women's Project
Asian and Pacific Islanders HIV/AIDS Coalition, New York, NY*

*Monica Johnson,
Member, Statewide Prevention Community Planning Group,
Columbia, LA*

Questions and Answers

12:05 pm - 12:30 pm

Taking Control: Research Update on Female Controlled Barrier and Chemical Methods for the Prevention of Heterosexual Transmission - Consort I

This session will provide an update on the progress in the development of female controlled barrier methods such as the female condom and chemical methods (microbicides) to prevent heterosexual transmission of HIV infection. The presenter will provide an overview of the research that has been undertaken and is currently underway in the development of barrier methods that women can control and discuss future directions for research.

*Dora Warren, Ph.D.,
Acting HIV Coordinator, Division of Reproductive Health,
National Center for Chronic Disease Prevention and Health
Promotion, Centers for Disease Control & Prevention, Atlanta, GA*

Questions & Answers

12:30 pm - 1:45 pm

Lunch on Your Own

1:45 pm - 3:15 pm

Concurrent Workshops

A) HIV Community Planning: Increasing the Participation of Women of Color

This workshop will provide an overview of the community planning process in HIV prevention. The presenters will discuss parity, inclusion and representation issues and barriers to participation in community planning. They will also explore strategies to increase the participation of women of color in the community planning process.

*Jacqueline Coleman
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National Minority AIDS Council, Washington, DC*

Beri Hull
Community Education Coordinator
National Association of People with AIDS, Washington, DC

Mary Sanchez Bane
Community Liaison
U.S. Mexico Border Health Association, El Paso, TX

Gwen Bampffield-Wright,
Director of Prevention & Care Services
The ACCESS Network, Inc., Hampton, SC

Questions and Answers

B) The Impact of HIV Partner Notification and Names Reporting on Prevention Efforts Among Women of Color

Embassy Room

This session will explore the current and proposed policies regarding HIV partner notification and HIV names reporting. The implications of these policies will be discussed in terms of their impact on HIV prevention efforts among women of color.

Miguelina Leon,
Director of Government Relations,
National Minority AIDS Council, Washington, DC

Pandora Singleton,
Executive Director
Project Azuka, Inc., Savannah, GA

Silma González
Executive Director
Fundación SIDA Pediátrico, Santurce, PR

Questions and Answers

Non-traditional Approaches to HIV Prevention

Consort II Room

This session will describe a variety of strategies that use non-traditional approaches to provide HIV prevention services to women of color. Presenters will highlight approaches that incorporate holistic, spiritual and cultural elements (such as rites of passage) in the interventions.

*Sophia Jones-Redmond, MA
Director of Prevention and Education
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*Ann Luecha,
WOW Prevention Specialist
Asian Pacific AIDS Intervention Team, Los Angeles, CA*

*Louella Rhodes
Executive Director
Columbus Wellness Program (Extended Sisters), Columbus, GA*

*Elena Alvarado,
Director HDI Projects/HIV/AIDS Programs, Washington, DC*

*Toni Tsatoke
Program Assistant
American Indian Community House, New York, NY*

Questions and Answers

3:15 pm - 3:30 pm

Break

3:30 pm - 5:00 pm

Breakout Sessions - Continued

Facilitated breakout sessions by subpopulation of women of color will continue and focus on developing specific recommendations regarding the components of HIV prevention programs for specific populations/ groups. Participants will continue the discussion of the key HIV prevention issues and challenges for women of color for the particular subpopulations they are addressing in their breakout session. Additional examples of strategies that have worked with these subpopulations will also be discussed. Facilitators will lead a discussion to generate from the participants their perspectives on the HIV prevention needs of these groups and the socio-cultural, economic, and psychological factors that impact on HIV prevention. The group members will also identify the specific HIV strategies they feel will work to reduce the risk of HIV infection and promote behavioral changes among the subpopulations they are addressing. Facilitators will build on the previous day's session and generate specific

recommendations from participants regarding the components of tailored HIV prevention interventions for the subgroups discussed in the session.

A) Women of African Descent Continental Room

B) Latinas Consort II Room

C) Asian & Pacific Islanders Oak Room

D) Native Americans Embassy Room

5:00 pm - 5:15 pm

Break

5:15 pm - 7:00 pm

Special Performance

"No Le Digas A Nadie" (Don't Tell Anybody)

Consulate Room

An original work commissioned by Diverse Works and AVES, created by Elia Arce, a Costa Rican multi-media artist currently living in Los Angeles. The original work features three HIV+ Latinas from Central America, who tell their stories, as mothers, Spanish-speaking immigrants in a strange country and as Latinas who share the experience of having HIV. Performed in Spanish with English translation.

6 pm - 8:00 pm

Affinity Group Sessions

Consort II Room

Continental Room

Embassy Room

Wednesday, June 25, 1997

8:00 am-9:00 am

Registration & Continental Breakfast

Grand Foyer

9:00 - 9:10 am

Welcome and Announcements

Consort I

*Miguelina Leon,
Director of Public Policy,
National Minority AIDS Council,
Washington, DC*

9:10 - 9:25 am

Opening Remarks

*Marsha Martin, DSW
Special Assistant to the Secretary
United States Department of Health and Human Services*

9:25 am – 9:55 am

Opening Plenary

New HIV/AIDS Drug Therapies: Implications for Access to Care for HIV+ Women of Color

Consort I

This session will provide an update on the new antiretroviral therapies, the resulting changes in the standard of care for HIV and the implications for access to care for HIV+ women of color. The presenter will examine the relationship between the use of AZT monotherapy to reduce perinatal HIV transmission and the use of combination therapies and protease inhibitors to manage HIV disease. The presenter will also discuss the changing standards of care for pregnant HIV+ women and the revisions that are currently underway of the U.S. Public Health Service Guidelines for the use of AZT for HIV+ pregnant women.

Carmen Zorrilla, M.D., M.P.H.

*Professor, Department of Obstetrics & Gynecology,
University of Puerto Rico, School of Medicine, San Juan, PR*

Questions and Answers

9:55 am – 10:20 am

Update on Research on HIV Care for Women: Recent Findings of the HEERS Study

Consort I

This presentation will provide an overview of the clinical research currently being conducted on women with HIV and discuss recent findings of the HEERS study. The presenter will also discuss the implications of the findings for HIV care for women.

Dawn K. Smith, M.D., M.S., M.P.H.

Medical Epidemiologist

*Division of HIV/AIDS Programs, National Center for HIV, STD
& TB Prevention, Centers for Disease Control & Prevention,
Atlanta, GA*

Questions and Answers

10:20 am – 10:35 am

Break

10:35 am – 10:55 am

Innovations in HIV Care for Women

Consort I

This session will provide an overview of the Special Projects of National Significance (SPNS) programs which have been funded by HRSA to develop innovative care delivery systems for women with HIV and their families. The presenter will highlight programs in various settings that have developed

integrated responses to the complex care needs of poor, underserved women with HIV.

Katherine Marconi, Ph.D.

Director of the Office of Science and Epidemiology

Health Resources and Services Administration (HRSA)

Rockville, MD

(15 minutes)

Questions and Answers

10:55 am - 12:00 pm

Responding to the Realities of Women's Lives: Providing a Comprehensive Continuum of Care Consort I

This session will provide a description of the key features of various health care programs that respond to the complex issues facing women of color living with HIV/AIDS. Presenters will highlight the approaches that are used within their programs to address the psycho-social, economic and cultural factors which impact on access to care for diverse populations of women of color. Presenters will also summarize the lessons learned and provide recommendations for improving access to HIV care for women.

Pamela Mahan-Rudolph, LMSW

*Program Coordinator, Women's Immunology Clinic UT-Houston
LBJ General Hospital, Houston, TX*

Betty Duran,

Director of Client Services/ Ahalaya Project

National Native American AIDS Prevention Center, Oakland, CA

Barbara Aranda-Naranjo, RN, MSN

*Associate Director, South Texas AIDS Center for Children and
Their Families, University of Texas Health Science, San
Antonio, TX*

Rachel Matillano,

Case Manager,

Asian & Pacific Islander Wellness Center, San Francisco, CA

Questions and Answers

12:00 pm - 12:30 pm

Women's Voices: Advocating for Access to Care - Consort I

Women living with HIV/AIDS will share their experiences as advocates for access to quality health care.

*Cordelia Thomas,
Health Educator
Ahalaya Project-Tulsa Office, Tulsa, OK*

*Mary Helen Gloria, Member
Mujeres Unidas Contra SIDA, San Antonio, TX*

*Margaret Campbell
Treatment Advocate
Multicultural AIDS Coalition, Boston, MA*

12:30 pm -1:45 pm

Lunch on Your Own

1:45 pm -3:15 pm

Concurrent Workshops

A) Increasing Access to Care: Culturally Competent HIV Care & Case-management Programs for Women Oak Room

This session focuses on the barriers to access to care experienced by women of color living with HIV. Presenters will describe the key elements of successful case management programs that have been designed to address those barriers. They will also discuss the complex medical and psycho-social needs of women living with HIV and their families and describe the continuum of care and support services needed to meet the needs of women of color of diverse cultural backgrounds. Presenters will describe the specific components of culturally competent, holistic, HIV care services.

*Diana Gubiseh-Ayala,
Care Coordinator
American Indian Community House, New York, NY*

*Caroline Makainai,
Hawaiian HIV Case Manager
Life Foundation, Honolulu, HI*

*Yvette Rivero
Coordinator
University of Miami School of Medicine,
Division of Obstetrics and Gynecology, Research, Miami, FL*

*Luella Rhodes,
Executive Director
Columbus Wellness Center (Extended Sisters), Columbus, GA*

Questions and Answers

B) Models of Integrated HIV Care and Support Services for Women and Their Children - Continental Room

Many women living with HIV who have children experience barriers to access to care because medical and psycho-social support services for both mother and child are fragmented. Very often these women are juggling multiple family responsibilities and tend to neglect their own health in order to ensure that their children receive quality care. Presenters will describe the HIV care and supportive services needs of women with children and present one-stop shopping service delivery models that integrate services for both women and their children.

Cynthia Flores

HIV Program Coordinator

*New York University Medical Center, Department of Pediatrics
Lower NY Consortium, New York, NY*

Lucia Bustamante,

Research Assistant

*South Texas AIDS Center for Children and Their Families
University of Texas Health Science Center, San Antonio, TX*

Renata Polk,

Study Coordinator

Baylor College of Medicine/

Department of Obstetrics and Gynecology, Houston, TX'

Vidalina Hoyle, Consumer

Connecticut Pediatric AIDS Program,

University of Connecticut Health Center, Middletown, CT

Betty Duran,

Director of Client Services/ Ahalaya Project

National Native American AIDS Prevention Center, Oakland, CA

Questions and Answers

C) Empowerment: A Survival Strategy for Women Living with HIV

Consulate Room

This workshop will focus on empowerment as a vehicle to enhance access to early interventions, and HIV care for women living with the virus. Presenters will describe the components of their programs which promote empowerment and describe how the strategies they utilize serve to increase access to care, increase consumers' participation in their own treatment,

prolong life and improve the health status of women living with HIV/AIDS.

Carmen Zorrilla, M.D., M.P.H.
Professor, Department of Obstetrics & Gynecology,
University of Puerto Rico, School of Medicine, San Juan, PR

Ana Rodriguez,
Program Coordinator
Women's Early Intervention Program (WEIP)
L.A. County Office of AIDS Programs & Policy, Los Angeles, CA

Mari Da Silva
Director of Women in Crisis,
Project Return Foundation, New York, NY

Kwan Bennett-Benbow,
Consultant , Women's Project
Asian and Pacific Islanders HIV/AIDS Coalition, New York, NY

Pandora Singleton,
Executive Director
Project Azuka, Inc, Savannah, GA

Questions and Answers

D) Promoting Empowerment Through Peer Led Support Services

Embassy Room

This session will provide descriptions of a variety of services developed by and for women of color living with HIV/AIDS to provide support and promote empowerment. Presenters will share their experiences in developing peer led support groups, treatment education and self advocacy programs and discuss the value of such programs in enhancing self esteem and improving the health of women living with HIV/AIDS.

Mary F. Moreno
HIV/AIDS Educator, Austin, TX

Malkia Kendricks,
Coordinator of Skills Development
Women of Color AIDS Coalition, Boston, MA

Elisa Mendez,
Member
Mujeres Unidas Contra SIDA, San Antonio, TX

*Edith Miller,
Member
Midland's HIV Task Force for Women, Columbia, SC*

*Ellen J. Jones,
Member, Native American Leadership Commission on
HIV/AIDS, New York, NY*

Questions and Answers

3:15 pm - 3:30 pm

Break

3:30 pm - 5:15 pm

Breakout Sessions

Facilitated breakout sessions by subpopulation of women of color. Participants will hear a 30 minute panel presentation on the key HIV care and support services issues and challenges for women of color for the particular subpopulations they are addressing in their breakout session. Examples of strategies that have worked to provide a continuum of comprehensive culturally competent services will also be provided. Facilitators will then lead a discussion to generate from the participants their perspectives on the HIV care & support services needs; the socio-cultural, economic, and psychological factors that impact on access to HIV care; and the specific HIV strategies which they feel will work to increase access to care, promote empowerment and enhance the health and quality of life for the women in the subpopulations they are addressing.

A) Women of African Descent Continental Room

B) Latinas Consort II Room

C) Asian & Pacific Islanders Oak Room

D) Native Americans Embassy Room

5:15 pm - 5:30 pm

Break

5:30 PM - 7:00 PM

Special Performance

Consulate Room

**"A Traditional Kind of Woman:
Too Much, Not 'Nuff"**

Vignettes of the lives of Native American women living with HIV/AIDS, commissioned by the American Indian Community House

*Introduction by Diana Gubiseh-Ayala,
American Indian Community House, New York, NY*

Performed by:
Hortencia and Elvira Colorado (Chichimec)
Coatlque Theatre Company

Thursday, June 26, 1997

9:00 am - 10:15 am

Ms. Foundation Women and AIDS Fund: Funding Strategies to Enhance Women Led and Focused HIV/AIDS Programs

Continental Room

This special session will provide participants with an overview of the goals and objectives of the National Women and AIDS Fund, sponsored by the Ms. Foundation for Women and review the upcoming request for proposal (RFP) process. There will also be a discussion of the mechanisms used to obtain community input in the RFP development process. This fund is geared towards supporting innovative HIV intervention and advocacy programs sponsored women-led and focused organizations and programs.

Irene Wamsler-Snow,
Program Coordinator
Women and AIDS Fund,
Ms. Foundation for Women, New York, NY

Miguelina Leon,
Advisory Board Member
Women and AIDS Fund,
Ms. Foundation for Women, New York, NY

10:15 am - 11:30 am

Breakout Sessions - continued

The facilitated breakout sessions by subpopulation of women of color will continue to meet to finalize discussion of the previous day and discuss the impact of managed care delivery systems on access to care for women of color. Facilitators will then lead a discussion to generate specific recommendations from the participants on the specific components of culturally competent and holistic HIV care and support delivery systems to meet the unique needs of the subpopulations they are addressing. Facilitators will also generate recommendations to improve access to care and support services for women within managed care delivery systems.

A) Women of African Descent Continental Room

B) Latinas Consort II Room

C) Asian & Pacific Islanders Oak Room

D) Native Americans Embassy Room

11:30 am - 11:45 am

Break

11:45 am - 1:30 am

Closing Plenary & Luncheon

Consort II Room

11:45 am - 12:00 pm

Special Presentation

Richard Brown,

Program Officer

The Phillip Morris Companies, Inc.

12:00 pm - 12:45 pm

Report Back From Break-out Groups

A) Women of African Descent

B) Latinas

C) Asian & Pacific Islanders

D) Native Americans

Closing Remarks

Miguelina Leon,

Director of Government Relations,

National Minority AIDS Council,

Washington, DC

Members of the Conference Planning Committee

Special Thanks to the Philip Morris Companies Inc., for their Generous Support of this Luncheon

Empowerment II: A Strategy for HIV/AIDS Prevention and Access to Care

Among Women of Color Conference - Memphis, Tennessee - August 9-11, 1998

Conference Objectives

- The Conference was designed to convene women of color from diverse ethnic/racial groups, service providers, researchers, policy makers and advocates to exchange information on new developments in HIV-prevention strategies, interventions, treatment and care.
- The conference focused on developing consensus on strategies to increase access to early HIV interventions, treatment and care for women of color.
- Participants examined culturally competent and language appropriate strategies and interventions designed to reduce the disparities in HIV incidence and AIDS related deaths experienced by women of color.
- Participants also had the opportunity to explore the implications of new drug therapies, and new testing technologies for HIV counseling and testing, prevention and access to care among women of color.

Prevention

- To provide opportunities for CDC to share with participants their plan to expand the AIDS surveillance system to include HIV surveillance as well as the role of HIV surveillance in monitoring the front end of the epidemic and in informing program planning and resource allocation for HIV interventions targeted to women.
- To provide opportunities for participants to examine how HIV name reporting may impact HIV testing behaviors among women of color and access to HIV prevention and care services.
- To provide opportunities for the CDC to share with participants the results of research focused on reducing HIV transmission and preventing HIV infection among women including: behavioral interventions, STDs treatment interventions that serve to reduce HIV transmission and infections, female controlled chemical and barrier methods, perinatal transmission research, the role of new HIV testing technologies; etc.
- To provide opportunities for participants to share information on innovative HIV prevention strategies that have improved HIV prevention outcomes for women of color in diverse communities.
- To provide a forum for participants to discuss and explore the implications of new testing technologies for HIV counseling and testing and primary and secondary prevention interventions.

Treatment and Care

- To provide opportunities for women of color living with HIV and service providers to share successful and innovative program strategies that have increased the number of women who learn their HIV sero status early and have improved access to early treatment interventions and supportive services designed to reduce HIV morbidity and AIDS mortality.
- To provide opportunities for HRSA staff, and conference participants to identify critical factors to be considered by managed care providers in developing services to meet the HIV-care needs of poor, underserved HIV+ women and their family networks.
- To provide opportunities for HRSA to share with participants the results of on-going HIV care and support service delivery and evaluation studies focused on women and to provide a forum for the discussion of the implications for population tailored service delivery, implementation and resource allocation.
- To provide a forum for women of color living with HIV/AIDS and service providers to discuss the potential impact of managed care service delivery systems on access to quality HIV care and supportive services for poor, underserved populations of women.

Format

The format for this three-and-one-half-day working conference was designed to promote the exchange of the socio-cultural perspectives and HIV experiences and expertise of the diverse participants; to provide updates on the progress of HIV prevention research and interventions; and to provide updates on the research and programs related to HIV clinical care for women, the impact of new drug therapies on HIV/AIDS morbidity and mortality among women of color, the new clinical guidelines for HIV care, treatment adherence and HIV clinical care and supportive service designs for women of color.

The format was also designed to facilitate working sessions to expand knowledge and understanding of the implications of ethnic/racial and demographic diversity for HIV counseling and testing, prevention interventions and care service models for women of color.

Sub-population breakout sessions explored the applicability of the research findings and interventions/program models for improvement of HIV prevention/care services among these groups. Sessions also focused on developing consensus on the key elements of HIV prevention/care service models/interventions tailored for particular subpopulations of women of color.

National Minority AIDS Council Empowerment II Conference

August 9-12, 1998

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Empowerment II

A Strategy for HIV Prevention and Access to Care Among Women of Color

Agenda

Sunday, August 9, 1998

12:00-3:00 p.m.

Arrival and Registration

Grand Ball Room & Foyer 15th Floor

3:00-5:00 p.m.

Opening Plenary Session

Grand Ball Room & Foyer 15th Floor

WELCOME AND ACKNOWLEDGMENTS

Miguelina Leon

Director, Government Relations/Policy

National Minority AIDS Council

OPENING CEREMONY

Monica Johnson

Columbia, LA

CLOSING THE GAP IN HIV/AIDS HEALTH STATUS AND SURVIVAL FOR WOMEN OF COLOR

Gwen Carter

Life Force: Women Fighting AIDS, Brooklyn, NY

Suki Terada Ports

Family Health Project, New York, New York

Cynthia Claus

Phoenix, AZ

Miguelina Leon

National Minority AIDS Council, Washington, DC

Questions, Answers, & Discussion

5:30-7:30 p.m.

RECEPTION Memphis Ball Room 15th Floor

NETWORKING

ENTERTAINMENT

Monday, August 10, 1998

8:00 a.m.-6:00 p.m. **PWA Lounge Open** Board Room 14th Floor

8:00-9:00 a.m. **REGISTRATION/CONTINENTAL BREAKFAST**
Grand Ball Room & Foyer 15th Floor

9:00-10:30 a.m. **GENERAL SESSION I**
Grand Ball Room 15th Floor

EPIDEMIOLOGY OF HIV/AIDS AMONG WOMEN OF COLOR: SOCIO-DEMOGRAPHIC PERSPECTIVES

*Dr. Helene Gayle,
Director, National Center for HIV, STDs and TB Prevention,
Centers for Disease Control and Prevention
Atlanta, GA*

FEDERAL RESPONSE TO THE HIV/AIDS EPIDEMIC AMONG WOMEN OF COLOR

*Dr. Marsha Martin
Special Assistant to the Secretary of the U.S. Department of
Health & Human Services
Washington, DC*

*Francess E. Page, RN, MPH
Senior Health Advisor, U.S. Public Health Service,
Office of Women's Health
Washington, DC*

*Dr. Helene Gayle,
Director National Center for HIV, STDs and TB Prevention,
Centers for Disease Control and Prevention
Atlanta, GA*

*Eugenia Foster Adams
Project Officer, HIV/AIDS Bureau,
Health Resources and Services Administration
Rockville, MD*

Questions, Answers, & Discussion

10:30-10:45 a.m. **BREAK**

10:45 a.m.-12:15 p.m. **GENERAL SESSION II**
Grand Ball Room 15th Floor

MONITORING THE FRONT END OF THE EPIDEMIC: IMPLICATIONS FOR HIV SURVEILLANCE & NAMES REPORTING FOR WOMEN OF COLOR

*Dr. Helene Gayle,
Director National Center for HIV, STDs and TB Prevention,
Centers for Disease Control and Prevention
Atlanta, GA*

*Yvette Rivero
University of Miami OB/ CYN Research Program
Miami, FL*

*Leanne Guy
HIV/STD Prevention Project
Inter-Tribal Council of Arizona, Inc.
Phoenix, AZ*

Questions, Answers & Discussion

12:15-1:45 p.m.

LUNCH ON YOUR OWN

1:45-3:30 p.m.

CONCURRENT WORKSHOPS SESSION I INNOVATIVE HIV PREVENTION INTERVENTIONS

WORKSHOP I

Grand Ball Room 15th Floor

STRATEGIES TO REACH YOUNG WOMEN OF COLOR

*Nancy Rivera
Chicago Department of Health
Westtown Neighborhood Health Clinic, Chicago, IL*

*Leanne Guy
HIV/STD Prevention Project
Inter-Tribal Council of Arizona, Inc., Phoenix, AA*

*Ivonne Ocasio
Taller Salud, Inc., San Juan, PR*

*Mary Lee Gray
County of Los Angeles, Department of Health
Services, Adolescent Unit-Office of AIDS Programs,
Los Angeles, CA*

WORKSHOP II

Magnolia Room 14th Floor

STRATEGIES TO REACH UNDERSERVED & RURAL WOMEN

Gwen Carter

Life Force: Women Fighting AIDS, Brooklyn, NY

Laverne Dallas

*Hopi Tribe: Behavioral Health Services,
Second Mesa, AZ*

Rosa Benedicto

*U.S. Mexico Border Health Association,
El Paso, TX*

Rebecca Helem

National Minority AIDS Council, Washington, DC

WORKSHOP III

Delta Room 14th Floor

SOCIO-CULTURAL CONSIDERATIONS IN HIV/STD PREVENTION INTERVENTIONS

Sheila Dennie

*Tennessee AIDS Education & Training Center,
Nashville, TN*

Maria Isabel Baez Arroyo

Fundación SiDA de Puerto Rico, San Juan, PR

Cecelia Chung

Asian and Pacific Islander Wellness Center, San Francisco, CA

WORKSHOP IV

Memphis Ballroom 15th Floor

HIV PREVENTION CASE MANAGEMENT PROGRAMS

Cecilia (Cissy) Elm, MSW/CSW

*American Indian Community House, Inc.,
Syracuse, NY*

Nilda Soto

PROCEED, Inc., Elizabeth, NJ

Alona Karen Catamco

Asian and Pacific Islander Wellness Center, San Francisco, CA

Paulette E. Forbes, MSN, RN

Robert Wood Johnson Pediatric Program, New Brunswick, NJ

3:30-4:00 p.m.

BREAK

4:00-5:30 p.m.

BREAK-OUT WORKGROUPS BY SUB-POPULATIONS

STRATEGIES TO REDUCE HIV INFECTION

A) African Americans Grand Ball Room 15th Floor

B) Asians & Pacific Islanders Delta Room 14th Floor

C) Latinas Memphis Ball Room 15th Floor

D) Native Americans Magnolia Room 14th Floor

ADJOURN

Tuesday, August 11, 1998 Agenda

8:00 a.m.-6:00 p.m.

PWA LOUNGE OPEN

Board Room 14th Floor

8:00-9:00 a.m.

REGISTRATION/CONTINENTAL BREAKFAST

Grand Ball Room & Foyer 15th Floor

9:00-10:30 a.m.

GENERAL SESSION III

Grand Ball Room 15th Floor

**THE STATE OF THE ART OF HIV PREVENTION AND
CARE FOR WOMEN: 12TH WORLD AIDS
CONFERENCE GENEVA UPDATE**

Dr. Carmen Zorilla

University of Puerto Rico School of Medicine

San Juan, PR

**HIV PREVENTION: BEHAVIORAL INTERVENTIONS
FOR WOMEN OF COLOR**

Dr. Gina Wingood

Emory University Rollins School of Public Health,

Atlanta, CA

DEVELOPING A STANDARD OF HIV PREVENTION FOR WOMEN

*Tonia Schaffer, MPH
HIV/AIDS Public Policy & Programs,
Chicago Department of Health*

Questions, Answers, & Discussion

10:30-10:45 a.m.

BREAK

10:45 a.m.-12:15 p.m.

GENERAL SESSION IV

Grand Ball Room 15th Floor

THE ROLE OF NEW HIV TESTING TECHNOLOGIES IN PREVENTION AND ACCESS TO CARE FOR WOMEN

*Deane Taylor
Cook County Hospital, Women & Children's HIV Program
Chicago, IL*

*Maria Alvarez
PROCEED, Inc. Elizabeth, NJ*

*Nikki Calma
Asian and Pacific Islander Wellness Center,
San Francisco, CA*

Questions, Answers & Discussion

12:15-1:45 p.m.

LUNCH ON YOUR OWN

1:45-3:30 p.m.

CONCURRENT WORKSHOPS SESSION II

WORKSHOP I

Grand Ball Room 15th Floor

MANAGED CARE: IMPLICATIONS FOR HIV CARE DELIVERY FOR SPECIAL POPULATIONS

*Rebecca Helem
National Minority AIDS Council, Washington, DC*

*Dr. Barbara Aranda-Naranjo, PhD., RN
University of the Incarnate Word,
School of Nursing, San Antonio, TX*

*Diana Gubiseh Ayala
American Indian Community House, New York, NY*

*Anna Wyman
University of Miami, Department of Pediatrics,
Miami, FL*

*Rachel Matillano
Asian and Pacific Islander Wellness Center,
San Francisco, CA*

1:45-3:30 p.m.

CONCURRENT WORKSHOPS SESSION II

WORKSHOP II

Memphis Ball Room 15th Floor

INCREASING ACCESS TO HIV CARE: FOR RURAL AND MIGRANT/IMMIGRANT WOMEN

*Lydia Rodriguez
William F. Ryan Community Health Center,
New York, NY*

*Andrea Sewell
Louisiana State University Medical Center
(LSUMC), Monroe, LA*

*Selina Catalá, MS, LCDC
University of Texas Health Science Center,
San Antonio, TX*

*Caroline Makainai
The Life Foundation, Honolulu, HI*

WORKSHOP III

Magnolia Room 14th Floor

INCREASING THE PARTICIPATION OF WOMEN OF COLOR IN HIV PLANNING/DECISION-MAKING PROCESSES

*Miguelina Leon
National Minority AIDS Council, Washington, DC*

*Gloria Nieto
People of Color AIDS Foundation, Santa Fe, NM*

*Karen McManus
Women of Color AIDS Council, Boston, MA*

1:45-3:30 p.m.

CONCURRENT WORKSHOPS SESSION II

WORKSHOP IV

Delta Room 14th Floor

FACILITATING ACCESS TO CARE: CASE MANAGEMENT AND SUPPORT SERVICES

Vera Franklin

Ahalaya Project, Oklahoma City, OK

Clarita Santos

Asian American AIDS Services, Chicago, IL

Yvette Rivero

*University of Miami OB/GYN Research Program
Miami, FL*

Shonda Harvey

South Dallas Health Access, Dallas, TX

3:30-4:00 p.m.

BREAK

4:00-5:30 p.m.

BREAK-OUT WORKGROUPS BY SUB-POPULATIONS

STRATEGIES TO INCREASE ACCESS TO CARE

A) African Americans Grand Ball Room 15th Floor

B) Asians & Pacific Islanders Delta Room 14th Floor

C) Latinas Memphis Ball Room 15th Floor

D) Native Americans Magnolia Room 14th Floor

5:30-6:30 p.m.

AFFINITY GROUP SESSIONS

ADJOURN

Wednesday, August 12, 1998 Agenda

8:00 a.m.-6:00 p.m.

PWA LOUNGE OPEN

Board Room 14th Floor

7:30-8:30 a.m.

CONTINENTAL BREAKFAST

Grand Ball Room 15th Floor

8:30-10:99 a.m.

GENERAL SESSION V

IN OUR OWN VOICES: PANEL PRESENTATION

**WOMEN OF COLOR LIVING WITH HIV/AIDS
PERSPECTIVES ON STRATEGIES TO IMPROVE CARE
AND SUPPORT ADHERENCE TO TREATMENT**

GiGi Nicks

*Women & Children's HIV Program, Women's Advocacy,
Cook County Hospital, Chicago, IL*

Mary Helen Gloria

Mujeres Contra El SIDA, San Antonio, TX

Alliena Baker

WORLD, San Francisco, CA

Lorraine Ann Taylor

Bronx, New York

Juanita Peralta

Corazones Unidas, Santa Fe New Mexico

10:00-10:15

BREAK

10:15-11:45 a.m.

BREAK-OUT WORKGROUPS BY SUB-POPULATIONS

**FINALIZE RECOMMENDATIONS:
STRATEGIES TO REDUCE HIV INFECTION AND
INCREASE ACCESS TO CARE**

A) African Americans Grand Ball Room 15th Floor

B) Asians & Pacific Islanders Delta Room 14th Floor

C) Latinas Memphis Ball Room 15th Floor

D) Native Americans Magnolia Room 14th Floor

12:00 p.m.-2:30 p.m.

LUNCHEON

**BREAK WORKGROUPS REPORT BACK TO LARGE
GROUP: RECOMMENDATIONS FOR CDC AND HRSA**

ADJOURN

Funded by

The Centers for Disease Control & Prevention

The Ford Foundation

The Health Resources & Services Administration HIV/AIDS Bureau

The Public Welfare Foundation

The U.S. Public Health Service Office of Women's Health

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